Title: The EAST-Dem study: Encouraging Access for South Asians to Timely Dementia Diagnosis.

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Declaration

I wrote the application for funding and was awarded an NIHR Doctoral Research Training Fellowship in order to carry out the work in this thesis. I conducted the literature searches, screening of abstracts and titles, data extraction, quality ratings and synthesis of findings for the systematic review. I analysed data for the observational study on dementia diagnosis and wrote up my findings. I applied for and obtained ethical approval for the qualitative study, piloting work and pilot randomised controlled trial. I conducted all interviews and co-facilitated all focus groups for the qualitative study, read and independently coded transcripts and wrote up the findings. I used findings from my systematic review and qualitative work to design and refine an intervention to encourage help-seeking for dementia at an earlier stage in South Asians.

I collaborated with Julia Hailstone (a DClinPsy student from Royal Holloway, University of London) on a study which used findings from focus groups to design and validate a questionnaire to measure attitudes to help-seeking for dementia among South Asians. I recruited GP practices, recruited and followed up all participants in the pilot randomised controlled trial, collected and analysed all data and wrote up my findings.

I, Naaheed Mukadam confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

30th June 2017 [redacted]

Date Naaheed Mukadam

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I am grateful to all the community organisation leaders who helped arrange focus groups and to all research participants for taking part and helping me to complete this work.

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Abstract

Background: People from Black and Minority Ethnic backgrounds tend to seek help later in the course of dementia than people from the majority ethnic population.

Aim: To develop an intervention to encourage people from South Asian backgrounds to seek help earlier for memory problems and test its acceptability and feasibility.

Methods: I systematically reviewed the literature and analysed routinely collected data to find interventions which improved dementia diagnostic rates. I then completed my qualitative study with South Asian community members to inform the development of an intervention to encourage earlier help seeking for memory difficulties by South Asian people. After piloting, I tested the intervention in a pilot cluster randomised controlled trial (RCT) with South Asian patients from participating GP practices. Primary outcomes were:

1. Feasibility - recruitment and retention rates
2. Acceptability - rating on a Likert scale.

Results: No trials to increase dementia diagnosis rates have been successful, but rates increased significantly after implementation of the English National Dementia Strategy. South Asian community members said that understanding,

through a story, that dementia was a physical illness, would normalise dutiful family members seeking interventions. I developed a bilingual leaflet and trilingual DVD with this content. I recruited and randomised 8 GP practices; 78/102 (76%) patients who allowed me to contact them, consented to the study (37 treatment-as-usual and 41 intervention). 76 (97%) participated in follow-up. 37/41 (90%) who received the intervention found it acceptable.

Conclusion: I designed the first culturally-appropriate intervention to encourage help-seeking for dementia in the South Asian population. Participants found it acceptable. It was feasible to recruit and follow-up participants. A full-scale RCT would require a very large number of GP practices to participate so is likely to be expensive. It may be preferable to make this acceptable and simple intervention available and disseminate it.

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1 : Introduction

1.1 South Asians and dementia

> *"He wouldn't sleep at night and then we'd put him in bed, he'd get up and then he'd be calling out for us to help him get back into bed. He'd wake up in the middle of the night and just strip his bed clothes …and say that someone's trying to get in, someone's trying to kill him through the window, things like that, hallucinations really. One day he got really aggressive. Normally he'd get angry, he'd shout and then he'd calm down, so I called the GP because I got really scared because he was doing things that he'd never done before like was getting quite violent, he was throwing things about… "*

This account of her father's cognitive decline and associated aggression and psychotic symptoms was related to me by a Bangladeshi carer during a research interview I conducted prior to my PhD. I was struck by the family's determination to continue managing as best as they could at home and that they did not involve the GP until they were very frightened. Progressive cognitive decline was conceptualised as a reaction to having been in hospital many months previously and no outside help was sought until the man's aggression threatened his family, including the one year old child who lived in the family home. The family's loyalty and resourcefulness were admirable but I also felt saddened that they had endured several crises before they obtained the diagnosis of dementia and the support they and the patient needed.

This and other encounters with South Asian patients and carers stimulated my interest in attitudes towards cognitive decline in this ethnic group. I wanted to explore why South Asian people delayed seeking help for memory problems and whether they could be encouraged to do so earlier.

1.2 Scope of the thesis

I start by defining dementia and ethnic group and arguments for and against diagnosing dementia earlier in the illness process. I describe barriers and facilitators to help-seeking for dementia and how they may differ in minority ethnic groups. I explore what works in terms of increasing diagnosis rates of dementia, in a systematic review of interventions and observational cohort study using data from the Health and Social Care Information Centre. I then describe the process of designing an intervention to encourage earlier help-seeking in South Asians using qualitative interviews. I describe how I used findings from my qualitative work, alongside behaviour change theories and understandings about how timely diagnosis might be increased across all populations, to design an intervention to encourage South Asians to seek help earlier for dementia. Alongside the qualitative work, I collaborated on a project to design and validate a questionnaire to assess attitudes to help-seeking for dementia in South Asians which was an outcome in the subsequent trial. Finally I describe the pilot randomised controlled trial in which I evaluated acceptability and feasibility of my intervention.

I have published peer-reviewed articles about my systematic review, observational study, questionnaire development and validation and qualitative work. Copies of these papers can be found in the Appendix.

2 : Background

2.1 Dementia

Dementia is an acquired impairment of higher cognitive functions, such as language, memory, planning and visuo-spatial processing without the clouding of consciousness (World Health Organisation 1992). It can occur at any age but is much more common in older people, affecting one in fourteen people over the age of 65 and one in six over the age of 80 (Prince M. et al. 2014). The incidence of dementia roughly doubles with every five year increase in age (Jorm A.F. and Jolley 1998). In 1910-12, life expectancy at birth was 52 years for males and 55 years for females in the UK (Office for National Statistics 2009). Less than 100 years later, life expectancy for babies born in 2001 had risen to 76 years for males and 81 years for females (Office for National Statistics 2009). As people live longer, the proportion of older people in the population grows and so does the number of people with dementia.

2.2 An ageing population

Advances in medicine and the management of chronic illnesses have meant that people are living healthier as well as longer lives (Office for National Statistics 2012c). Dementia is one of the major contributors to disability in the older population and costs the global economy the equivalent of 1% of the world's gross domestic product annually (World Health Organization 2012).

It is estimated there are 850,000 people living with dementia in the UK, and the number of people affected is expected to increase to over one million by 2025 (Prince M. et al. 2014). As the population continues to age, the incidence as well as the prevalence of dementia would be expected to increase. However, there has been an unexpected observed decline in age-specific dementia incidence or prevalence rates in some countries, such as the United States (US), the United Kingdom (UK) (Matthews et al. 2016;Matthews et al. 2013;Office for National Statistics 2012b), Sweden (Qiu et al. 2013), the Netherlands (Schrijvers et al. 2012), and Canada. In contrast, there have been reports of an increase in incidence rates in China (Chan et al. 2013) and prevalence rates in Japan (Dodge et al. 2012;Okamura et al. 2013), while rates in Nigeria are stable (Gao et al. 2016). It is unclear what is behind the observed decreases in incidence and prevalence but it is likely to be a combination of factors relating to better vascular health and improved cognitive reserve, particularly through better access to education (Langa et al. 2016;Satizabal et al. 2016).

There may, therefore, be the potential to reduce the risk of dementia in future by modifying risk factors such as physical inactivity, obesity, diabetes and hypertension that are known to be associated with developing the disease (Norton et al. 2014). However, current trends for increasing midlife rates of obesity and associated ill-health are projected to lead to a 19% increase in dementia rates in China and 9% in US (Loef and Walach 2013).

Although the incidence in specific age-groups may be modified, overall the number of people with dementia will rise with time as the population ages, and it remains probably the most important health problem in economic terms, costing the UK economy £26.3 billion per year (Alzheimer's society 2014).

The most common type of dementia, accounting for approximately 60% of cases, is Alzheimer's disease (Knapp M. and Prince M. 2007). About a third of dementia is either vascular or of mixed vascular and Alzheimer's pathology (Knapp M. & Prince M. 2007).

2.3 The benefits of a timely diagnosis of dementia

A timely diagnosis of dementia is one made as early as possible in order to minimise the risks of impaired cognitive function, provide support and enable the person with dementia to plan for the future while they retain mental capacity to do so (Prince M. et al. 2011). Alternatively it can be defined as a diagnosis that occurs when the patient wants it or when the carers need it (NHS England 2015).

2.3.1 An individual's right to know

In the early 1990's the Fairhill guidelines on the ethics of the treatment of people with Alzheimer's disease concluded, after discussions between those who had dementia, their carers and a variety of professionals:

> *"Because individuals have a right to control their own lives, and because true control depends on knowing about oneself, individuals have a right to full disclosure regarding a dementia diagnosis." (Post and Whitehouse 1995)*

One survey of those diagnosed with dementia found that over 90% of people with dementia wanted to know their diagnosis and an even greater percentage of carers of people with dementia said they would want to know their diagnosis if they developed dementia (Pinner and Bouman 2003). Those presenting to medical services to obtain a diagnosis usually suspect there is a problem with their or their family member's cognition so a diagnosis is an anticipated possible outcome.

2.3.2 Psychological benefits for the person with dementia

Getting a diagnosis can help to end feelings of uncertainty (Bamford et al. 2004) and can help people to adapt and focus on their remaining capabilities rather than feeling negatively about declining abilities (Derksen et al. 2006).

A systematic review of the empirical data regarding disclosure of a dementia diagnosis found that, in addition to a person's right to know their diagnosis and the psychological benefits of knowing it, the most common reasons for disclosing a dementia diagnosis were the facilitation of planning for the future and maximising of treatment options (Bamford et al. 2004). Moreover, there is no evidence that receiving a diagnosis of dementia causes psychological distress, as evidenced by the observed stability of scores on a depression

scale and the slight reduction in scores on an anxiety scale after receiving a diagnosis (Carpenter et al. 2008).

2.3.3 Cognitive benefits for the person with dementia

Earlier studies of the association between baseline cognitive function and subsequent decline produced mixed findings. Some studies showed that progression of cognitive decline was unrelated to dementia severity at diagnosis (Stern et al. 1992) while others found that those with milder dementia had a faster decline in cognition (Thai et al. 1988). These were relatively small studies and a larger prospective study of 430 participants found that cognitive progression was slower in those diagnosed at an earlier stage of the illness (Morris et al. 1993). The reason behind this effect is unclear as the study was conducted before medication for treatment of dementia became widely available. It could reflect the natural progression of the illness. Now that there are psychological treatments for all dementias and pharmacological treating for AD treatments available, getting help earlier is likely to provide benefits.

2.3.4 Access to treatment

Currently, in the UK, the National Institute for Health and Care Excellence (NICE) recommends using cholinesterase inhibitors for the treatment of mild or moderate Alzheimer's dementia and memantine for moderate or severe Alzheimer's dementia (The National Institute for Health and Care Excellence 2006). These medications have a modest benefit on cognitive function and

help maintain a better level of function for longer compared to placebo (Bond et al. 2012). Continued treatment with medication has also been shown to reduce the risk of nursing home placement in people with moderate to severe dementia (Howard et al. 2015).

Cognitive stimulation therapy also has proven benefit on cognitive functioning in mild to moderate dementia (Spector et al. 2003). Obtaining a diagnosis of dementia early in the illness means that psychological and pharmacological treatment can start earlier. This has the potential to delay cognitive decline at an earlier stage.

2.3.5 Survival time after diagnosis

A population based cohort study of those diagnosed with dementia found a median survival time of 4.6 years in women and 4.1 years in men after initial diagnosis (Xie et al. 2008). An analysis of primary care data found a shorter median survival time in those with a new diagnosis of dementia than in the screened population (6.9 vs 10.7 years in those aged 65-69), with the highest mortality rate occurring in the first year after diagnosis. The authors suggest that this was possibly due to patients being diagnosed with dementia at a time of crisis or hospitalisation, and therefore relatively late in the illness (Rait et al. 2010). Again, these observations may simple reflect the natural progression of dementia and show that it progresses slowly initially then faster at a later stage.

2.3.6 Risk reduction

As people with dementia lose their abilities to manage their daily tasks, having access to clinical input following a diagnosis can ensure that regular risk assessments and management plans take place which can help ensure that the person with dementia is safe and avoids crises, for example by ensuring the person eats, has bills paid, has systems in place to take their medication safely, does not have a fire and only drives if safe.

In the UK there are a number of 'assistive technologies' available. This is a term used to describe any device or technology that enables a person to complete a task they would not otherwise be able to complete or to complete it with greater ease and safety (Sutherland 1999). The most common assistive technology is 'telecare' which involves monitoring a person with dementia remotely through community alarms which they can trigger to obtain assistance or through sensors and movement detectors which can help ensure a person's safety (Gibson et al. 2016). Having a diagnosis of dementia at an earlier stage enables people with dementia and carers to obtain these services earlier on in the illness, in a planned way and minimises risk.

2.3.7 Maximising mental capacity

Another aspect of knowing a diagnosis of dementia earlier in the illness is that the mental capacity to make complex decisions is relatively preserved early on. This means that, in the UK, people with dementia can make Advanced

Decisions about their future medical care, and they can draw up Lasting Power of Attorney which designates a person to make decisions on their behalf, should they lose the capacity to make these decisions for themselves. The legal framework for this is outlined in the Mental Capacity Act (2005) in the UK but these decisions can only be completed by a person who retains their mental capacity for these decisions, which is less likely as dementia advances.

2.3.8 Benefits and harm for carers or families of people with dementia

Receiving a diagnosis of dementia can enable family carers to reframe the observed symptoms of cognitive decline as being due to an illness rather than being the person's fault and carers expressed regret at not receiving the diagnosis sooner (Connell et al. 2004).

While carers of people with dementia are at high risk of developing depression or anxiety, a Cochrane review of 'cognitive reframing', which is altering unhelpful thoughts and adapting them to the situation, found that this strategy reduced anxiety, depression and subjective stress in carers of those with dementia (Vernooij-Dassen et al. 2011).

A coping-strategy based structured programme for carers of people with dementia reduced carers' depressive and anxiety symptoms for two years after the intervention and improved their quality of life (Livingston et al. 2013;Livingston et al. 2014). The effect on anxiety and depressive symptoms

was mediated by an increase in emotion-focused coping in those with case-level psychological morbidity at baseline (Li et al. 2014).

Over time there has been a greater focus on interventions such as counselling, stress management and carer education to improve psychological symptoms and distress in carers of people with dementia. A review of these psychosocial interventions found that the majority of them reduced carer psychological distress and some even improved patient mood (Brodaty et al. 2003). Another systematic review and meta-analysis of non-pharmacological interventions for carers of people with dementia found that providing these interventions to carers decreased the odds of admission of the person with dementia to a care home and increased time to care home admission (Spijker et al. 2008). This again highlights the potential benefits to obtaining a diagnosis and the earlier the diagnosis is obtained, the earlier these benefits could be reaped.

2.3.9 Benefits to wider society

Some researchers have proposed that the costs of setting up memory services to diagnose dementia earlier would theoretically be more than offset by the cost savings that may result if receiving support earlier delayed care home admission (Banerjee and Wittenberg 2009). One study used cohort data from 1285 individuals and cost estimates for care and institutionalisation to model the costs and benefits associated with current symptomatic treatments that can improve cognitive scores, as well as the theoretical benefits of disease-modifying treatment (Barnett et al. 2014). The authors found that the greatest

benefits for symptomatic treatments were early in the illness when cognition was relatively preserved. For theoretical disease-modifying treatments, treatment effect would be most beneficial and cost-effective at the point prior to cognitive decline, or around eight years earlier than most people with dementia are currently diagnosed. So the authors conclude that both for existing treatments and future theoretical ones, earlier diagnosis would be more cost-effective and earlier diagnosis should therefore be a priority.

2.4 Possible disadvantages of receiving an earlier diagnosis of dementia

In the absence of disease-modifying treatments, it is worth considering the disadvantages of receiving a diagnosis of dementia.

2.4.1 The right not to know

Although studies have found a high percentage of people would want to know their diagnosis, a small percentage of people stated they would not want to know (Pinner & Bouman 2003). People have the right of control over their own life, which needs to be balanced against the risks to themselves or others of not receiving support and care.

2.4.2 Psychological consequences of receiving a diagnosis

Like any serious and long-term condition, receiving a diagnosis of dementia can result in negative feelings including anxiety about declining abilities,

effects on personhood and self-esteem, stigma related to the diagnosis and possible reduction in activities (Bamford et al. 2004). Family members and spouses also have to adjust to the diagnosis and may feel burdened by the shift in responsibility that occurs after the diagnosis is made (Bunn et al. 2012).

2.4.3 Limitations of treatments

There are no medications that halt disease progression and prescribed medications are associated with side effects (Hager et al. 2014). One study found no effect of cholinesterase inhibitor treatment on survival, although this was a retrospective study (Suh et al. 2011).

Group cognitive stimulation therapy has a relatively small effect on cognition and effects are not present in an individualised version of this therapy (Orgeta et al. 2015).

Interventions to support carers show some benefits but even successful ones may not alter coping or how the carer perceives the burden of caring for the person with dementia (Vernooij-Dassen et al. 2011).

2.4.4 The possibility of misdiagnosis

As with any clinical syndrome, it is possible to misdiagnose dementia although the effects of this on patients and carers has not been examined. The sub-type of dementia may also be incorrectly diagnosed. One study found at post-mortem that Alzheimer's dementia was misdiagnosed in around 17% of people

followed up by a specialist assessment centre and as a result would have been taking medication inappropriately (Gaugler et al. 2013).

2.5 Conclusions

There is a lack of disease-modifying treatments but there is still much that can be done to improve the lives of those with dementia and their family carers, especially if dementia is diagnosed earlier. By moving towards earlier diagnosis, we ensure people with dementia get access to the best available treatments as soon as possible and that future advancements in treatments can be provided earlier in the illness. There are public health strategies and plans to increase the diagnosis rate for dementia in many countries, including the UK (Department of Health 2015).

2.6 Current UK dementia diagnosis rates

Less than 10 years ago, it was estimated that under a third of people with dementia ever receive a diagnosis (Department of Health 2009) but this has risen over time to nearer half (Department of Health 2013) and then 67% (Parkin and Baker 2016). In the UK, diagnosis rates vary in different areas from less than a third to over 75% of those estimated to have dementia, although this may not be timely diagnosis (Alzheimer's society 2013).

2.7 Ethnicity

Most developed countries have a sizeable ethnic minority population. Ethnicity is a complex construct which has varied in definition over time. Ethnic groups

are generally considered to be those that share a common ancestry, culture, historical memories, an attachment to a homeland and feel a sense of solidarity with one another (Hutchinson J. and Smith A.D. 1996). In the UK, minority ethnic people account for 15% of the English population and 39% of the London population (Office for National Statistics 2007).

Minority ethnic communities vary greatly between countries. In the UK, after Irish and other non-UK white groups, Indian and Pakistani ethnic groups are the largest ethnic minority groups (Office for National Statistics 2012a). In England and Wales, around 7% of the population is of Asian origin, with 2.5% of people describing themselves as Indian, 2.0% as Pakistani, 0.8% Bangladeshi and 1.5% as Other Asian (Office for National Statistics 2012a).

The South Asian population in the UK is younger than the White British population, with around 5% of the population older than 65 years compared to around 18% of the White British population (Office for National Statistics 2015). The ethnic minority population as a whole is predicted to increase to 27% of the population by 2026 and the proportion of older people within those ethnic minority groups, including South Asians, is also predicted to increase (Lievesley N. 2010). The prevalence of dementia will therefore rise in this group of people over time.

2.8 Dementia in the South Asian population

2.8.1 Dementia prevalence

The age-standardised prevalence of dementia in lower income countries such as India has been found to be much lower than in the UK (Kalaria et al. 2008). However, prevalence estimates vary depending on methods of screening used. One study found the prevalence of dementia in India to be around a quarter of the prevalence found in European countries if standard diagnostic techniques are used but more than double the European prevalence if a cross-culturally validated cognitive screening tool was used (Rodriguez et al. 2008). Within the UK, one study of 100 people over the age of 65 years in Bradford, found that South Asians had a prevalence of dementia of 4% compared to the general population prevalence of 2-8% reported in other studies at that time (Bhatnagar and Frank 1997). Another study based in Liverpool found the prevalence to be 9% in a sample of 418 people over 65 years of age but the number of South Asians in this group was relatively small (only 13 out of 418 people) so this may not be an accurate estimate (McCracken et al. 1997).

There have not been any large population-based surveys of the prevalence of dementia in South Asians in the UK although it has been assumed rates for dementia are similar to the White British population or are likely to be higher because of the two to three times higher risk of diabetes in South Asians (Tillin et al. 2013) which is known to be an important risk factor for developing dementia (Norton et al. 2014).

2.8.2 Survival times of South Asians after diagnosis

A recent population-based 14 year cohort study in the US found that, contrary to what one might expect, survival after dementia diagnosis was longer in people from minority ethnic groups. Survival was longest for Asian-Americans (4.4 years) and shortest in whites (3.1 years) (Mayeda et al. 2017). It is important to bear in mind that this is a US-based study, where Asian-Americans primarily includes people of East Asian origin, who tend to be more educated than the White population (United States Census Bureau 2012). Higher levels of education are associated with earlier diagnosis of dementia (Bowler et al. 1998), and the effect of education on enhancing survival in dementia is more pronounced in minority ethnic groups (Reuser et al. 2011). In the UK, in contrast, most British Asians are of South Asian origin and there are no reported educational advantages compared to the White population (Office for National Statistics 2012b).

2.8.3 Service use

People from ethnic minority groups use less dementia services in Western countries including the USA, UK and Australia (Cooper C et al. 2010). This review found that people from minority ethnic groups presented to dementia diagnostic services later in their illness and once diagnosed, were less likely to be prescribed cholinesterase inhibitors and to enrol in research trials. A later Danish study found that of all people with a diagnosis of dementia recorded on a national healthcare database, those from minority ethnic groups were less

likely to be prescribed cholinesterase inhibitors compared to the majority population (Stevnsborg et al. 2016). In a London-based memory service people from minority ethnic backgrounds had lower scores on cognitive testing at initial presentation to the service compared to the White British population, indicating later help-seeking at a more advanced stage of their dementia (Tuerk and Sauer 2015).

2.9 Why do minority ethnic communities use less dementia services?

Whilst there is considerable variation within South Asian people in terms of country of origin, language, religion, socio-economic power, and experiences there is also enough shared culture with regards to family structures, identity and health beliefs to make ethnicity a relevant factor with respect to health behaviours (Ahmed S.M. and Lemkau J.P. 2000). Furthermore, culturally-informed health beliefs and attitudes have been shown to be linked to help-seeking for health problems (Sheikh and Furnham 2000) so this is an important consideration in any research aimed at understanding or changing health behaviours.

2.9.1 Barriers to seeking help for dementia

As outlined earlier, there is widespread under-diagnosis of dementia. Although symptoms of dementia are recognised, many people with dementia or their carers believe the symptoms to be due to normal ageing or are reluctant to seek help (Bunn et al. 2012). One review found that people from minority ethnic

groups seem to prioritise help-seeking for dementia less than the majority population. Accurate assessment of cognition is a challenge, especially for those who are not fluent in the language of the country they reside in (Daker-White et al. 2002). There also seems to be a greater prevalence of beliefs that symptoms of dementia are caused by normal ageing and greater concerns about the stigma of getting a diagnosis in the minority population (Bunn et al. 2012).

In my previous systematic review of ethnicity and pathways to care for dementia, I found 13 studies examining the reasons why ethnic minority people with dementia present later to diagnostic and/or therapeutic services, or the pathway of presentation (Mukadam et al. 2011b). The included studies reported that there was significant overlap in the barriers and facilitators to accessing dementia services reported in a broad range of minority ethnic groups. These are shown in Box 2-1 below. The three main categories of barrier to help-seeking for dementia in minority ethnic groups seem to be:

1. Knowledge related, i.e. different beliefs about aetiology and the purpose of a diagnosis.
2. Society related, i.e. the concern about stigma and cultural expectations of looking after your own relatives until you can no longer cope.
3. Healthcare related, i.e. hesitation in approaching healthcare professionals or any barriers within the healthcare system itself.

Barriers to help-seeking for dementia

- Belief that the symptoms were due to normal ageing
- Attributing the symptoms to other physical, spiritual or psychological causes
- Denial that there was a problem
- Normalisation of symptoms
- Feeling there was nothing that could be done for dementia
- Concerns about stigma related to dementia
- Perceived ethical imperative to care for ones' own family members
- Language barrier
- Lack of familiarity with help-seeking pathways
- Negative experiences of the healthcare service

Facilitators to help-seeking

- Knowledge about dementia

Box 2-1: Barriers and facilitators to help-seeking for dementia in minority ethnic groups

Most studies report findings from within all minority ethnic groups. Some studies have directly compared different ethnic groups. One of these compared attitudes to the caregiving role amongst different ethnic groups. People from minority ethnic groups were less likely to seek help for their caregiving roles as they saw caregiving as something “natural, expected and virtuous” (Lawrence et al. 2008). Another study explored ethnic differences in the help-seeking pathway for dementia and found that people from minority ethnic backgrounds were more likely to obtain a diagnosis of dementia due to a health crisis rather than in a smooth help-seeking pathway. People from these groups were also less likely to ever obtain a diagnosis of dementia (Hinton et al. 2004).

My previous qualitative study in London, involved individually interviewing family carers of people diagnosed with dementia from White, Asian and Black ethnic groups who had presented to memory services. This study found certain barriers to help-seeking seemed specifically to occur in minority ethnic groups. These included different beliefs about the aetiology of symptoms, concerns about stigma and the perceived benefit of looking after your own family until you could no longer cope. The value of a diagnosis alone was also felt to be less beneficial amongst minority ethnic carers compared to their White UK counterparts (Mukadam et al. 2011a). This study replicated findings from the study discussed above (Hinton et al. 2004) that people from minority ethnic groups tended to obtain a dementia diagnosis as a result of a crisis rather than

in a planned way. There was also overlap with findings from another qualitative study carried out in Bristol (The Bristol BME People Dementia Research Group 2017), and one review specifically focused on the experience of carers (Johl et al. 2014).

2.10 Summary

In this chapter, I have outlined the importance of timely diagnosis in dementia, the epidemiology of dementia in the minority ethnic population in the UK and why people from minority ethnic populations may seek help later for dementia. In the next chapters, I will explore possible influences on timely dementia diagnosis rates from two perspectives in order to inform development of my own intervention. In chapter 3 I will described the systematic review I carried out of interventions to increase detection of dementia or cognitive impairment. In chapter 4, I will describe the secondary data analysis study I carried out, exploring temporal trends in dementia diagnosis rates in the UK.

3 : A systematic review of interventions to detect dementia or cognitive impairment

I carried out this review to inform the development of my intervention by finding out which interventions had been efficacious in leading to earlier dementia diagnoses or increased dementia diagnosis rates. Although my intervention was to be targeted at the South Asian population, I chose not to narrow my search to interventions that had been targeted at people from minority ethnic groups. This was partly because previous familiarity with this topic had shown the relative lack of literature regarding minority ethnic groups and dementia. Additionally, I reasoned that I could learn from successful interventions aimed at the general population and apply design features and principles from them to my own intervention design.

This review was published in January 2015 in the International Journal of Geriatric Psychiatry (International Journal of Geriatric Psychiatry**,** Volume 30, Issue 1, pages 32–45). A copy of the paper can be found in Appendix 1.

3.1 Method

3.1.1 Search strategy

3.1.1.1 Databases

I searched Medline, Embase, PsycINFO, Allied and Complementary Medicine, CINAHL, System for Information on Grey Literature in Europe (SIGLE) and the Electronic Theses Online Service (EThOS) with no restrictions on date or language of publication. I hand searched references of included papers; contacted authors of included papers and experts in the field; and searched electronic databases for publications from authors active in this field of research; to try to identify further papers. Since early diagnosis is a UK government priority, I also searched the internet for government or local council initiatives and contacted the Alzheimer's Society, Age UK and UK councils with active dementia awareness programmes.

3.1.1.2 Search terms

I used both MeSH and free text terms for Dementia AND Diagnos* AND Interven*(OR Trial OR RCT) AND Improve OR Increase; up to 15th February 2013.

3.1.2 Inclusion criteria

I included original research papers reporting interventions that included a quantitative outcome reporting at least one of the following:

- the number of people with memory complaints presenting to health or social services
- the number of people with a new diagnosis of dementia or cognitive impairment
- the proportion of people with dementia who were accurately diagnosed
- the degree of cognitive impairment of people diagnosed with dementia

I included papers with a separate comparator group or reported outcomes before and after the intervention.

I excluded studies that only tested screening programmes for cognitive impairment without a second stage procedure to find out if the screen positive was a true “case”. I excluded studies that only reported dementia diagnostic confidence or diagnostic accuracy in hypothetical case studies. Meeting abstracts and letters were also excluded.

3.1.3 Identification of papers

I removed duplicate papers and then screened titles and abstracts. My co-author Nishin Kherani (NK) also independently screened them. I read all retained papers. The decision to include or exclude papers was agreed by

consensus; with consultation with a third author (GL) where necessary. Where potentially relevant data was not reported, I contacted authors of included papers to request it.

3.1.4 Data extraction

Data was extracted for each paper by NK and me independently to ensure we extracted all relevant data reliably.

I planned to assess publication bias using a funnel plot once all data on outcomes was extracted.

3.1.5 Quality assessment

I used the Centre for Evidence Based Medicine (CEBM) criteria for evaluation of Randomised Controlled Trials (http://www.cebm.net/index.aspx?o=1157 accessed 05.04.13) for all of the papers. Each paper was assessed against fourteen criteria and one point was given for each, so the possible validity score range was 0-14 (see Box 3-1: Quality assessment checklist). I rated quality independently from another co-author CC, and agreed final scores by discussion. If the answers to any of the quality assessment questions were unclear, I requested further information from the authors.

1. Reliable diagnosis of dementia. I included diagnosis using standard criteria or by a specialist service.

2. Outcome measure was valid. For the purposes of this review, outcome measures were those assessing timeliness of diagnosis or rate of diagnosis so that I could assess the quality of the interventions for those purposes. A point for validity was given if the authors used validated diagnostic tools, standard statistical measures to report these outcomes and if the methods used to gather this data were robust. These outcomes may not have been the primary outcome measure for the authors.

3. Outcome measure reliable.

4. Participant blinded to intervention group. Participants were defined as the person receiving the intervention designed to improve the identification of dementia or cognitive impairment and not those receiving any other intervention detailed in the study.

5. Rater blinded to intervention group.

6. Randomised controlled trial (and analysed as random).

7. If randomised then randomisation process adequate and well described. If not randomised, comparability of control group.

8. Adequate follow-up rate at primary outcome time. A point was awarded if at least 70% of participants were followed up.

9. All participants accounted for.

10. Power calculation, for my primary outcomes of interest.

11. Full details of power calculation.

12. Sufficiently powered on outcome (at least 80% power with 5% p value). This was assessed with regards to the outcome of interest and not the authors' stated primary outcome.

13. Intention to treat analysis.

14. Appropriate statistical methods. A point was awarded if the outcome of interest was calculated or if the raw data for this calculation was available in the paper.

Box 3-1: Quality assessment checklist

3.1.6 Data analysis

I calculated odds ratios for a dementia/cognitive impairment diagnosis between groups where possible. I planned to meta-analyse findings where three or more studies reported on sufficiently homogenous interventions using comparable outcomes, but no three studies met these criteria so I could not.

3.2 Results

3.2.1 Search

I included 13/2945 potential studies identified. Results of the search are summarised in a PRISMA diagram below.

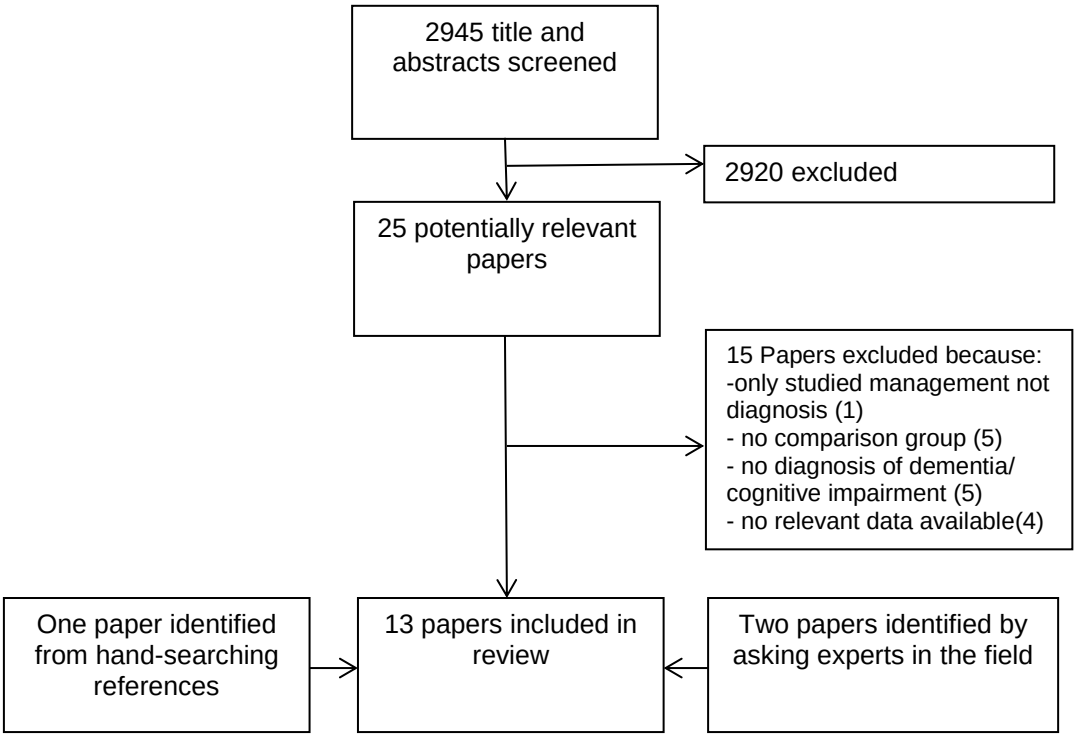

Figure 3-1: PRISMA diagram

I also found various local awareness campaigns during my search. None of these were suitable for inclusion in the study but they led to an observational study of dementia diagnoses over time which I describe in the next chapter.

3.2.2 Publication bias

I was unable to generate a funnel plot to assess publication bias, due to the wide variation in outcome measures. Six of the included studies reported significant positive results, two positive results with no test of significance and five negative results.

3.2.3 Study Characteristics

A breakdown of the quality scores is provided in Table 3-1. Quality scores ranged from zero to eight out of fourteen.

3.2.3.1 Setting

Nine studies were set in primary care, three in specialist settings and one in a nursing home. In general, studies in a specialist setting had a higher score for diagnostic accuracy but a lower score on other aspects such as sampling due to their more naturalistic study design, whereas studies in primary care had a more rigorous study design but lower diagnostic accuracy.

	Quality assessment item														
Paper	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**Total**
Banerjee et al 2007	Y	N	N	N	N	N	N	Y	Y	N	N	N	N	Y	**4**
Barton et al 2006	N	Y	Y	N/A	N	N	Y	Y	Y	N	N	N	N	Y	**6**
Boise et al 2010	Y	N	N	N	N	N	N	N	Y	N	N	N	Y	Y	**4**
Borson et al 2007	N	N	Y	N	N	N	N	Y	Y	N	N	N	Y	Y	**5**
Chan et al 2010	N	N	N	N	N	N	N	Y	Y	N	N	N	Y	Y	**4**
Downs et al 2006	N	N	N	N	N	Y	Y	Y	Y	N	N	N	Y	Y	**6**
Iliffe et al 2015	N	N	N	N	N	Y	Y	Y	Y	N	N	N	Y	N	**5**
Luce et al 2001	Y	Y	Y	N	N	N	N	Y	Y	N	N	N	Y	Y	**7**
Perry et al 2008	N	N	Y	Y	N	Y	N	Y	Y	N	N	N	Y	N	**6**
Pond et al 1994	N	Y	Y	N	N	N	N	Y	Y	N	N	N	N	Y	**5**
Ramakers et al 2011	Y	Y	Y	N	N	N	Y	N	Y	N	N	N	N	Y	**6**
Rondeau et al 2008	N	N	N	N	N	Y	N	Y	Y	Y	Y	Y	Y	Y	**8**
Seabrooke and Milne 2009	N	N	N	N	N	N	N	N	N	N	N	N	N	N	**0**

Table 3-1: Quality scores for individual papers

3.2.3.2 Comparator groups

Four of the studies were randomised controlled trials (RCTs), four used a non-randomised concurrent comparison group and five compared outcomes before and after the intervention.

3.2.3.3 Interventions

Most of the studies (n=7) tested educational interventions (Barton et al. 2006;Boise et al. 2010;Borson et al. 2007;Downs et al. 2006;Iliffe et al. 2013;Iliffe et al. 2015;Pond et al. 1994;Rondeau V. et al. 2008). These were very heterogeneous (see Table 3-2 for components of educational interventions).

Three studies evaluated the impact of introducing memory clinics (Banerjee et al. 2007;Luce et al. 2001;Ramakers and Verhey 2011); two leaflet campaigns (Chan et al. 2010;Seabrooke V. and Milne A. 2009) and one a geriatric liaison nurse assessment service (Perry et al. 2008).

Table 3-2: Components of educational interventions

Paper	Imparting knowledge						
	One-to-one	Group setting	Written information	Training to use screening tools	Decision support	Patient education	Specialist consultation
Barton et al 2006	X	X	X		X		X geriatric nurse visits weekly
Boise et al 2010	X		X		X	X information sheets for caregivers	
Borson et al 2007			X	X			
Downs et al 2006	X	X			X		
Iliffe et al 2013		X			X		
Pond et al 1994	X	X					
Rondeau et al 2008		X		X			

3.2.4 Outcomes

Primary outcomes were: dementia diagnosed by specialists using validated measures (6 studies) (Banerjee et al. 2007;Boise et al. 2010;Luce et al. 2001;Pond et al. 1994;Ramakers & Verhey 2011;Rondeau V. et al. 2008); a record of cognitive impairment or dementia diagnosis in participants' medical notes (6 studies) (Barton et al. 2006;Borson et al. 2007;Chan et al. 2010;Downs et al. 2006;Iliffe et al. 2013;Perry et al. 2008); and the numbers of people presenting to their GP with memory complaints (one study) (Seabrooke V. & Milne A. 2009). In addition, two studies (Barton et al. 2006;Luce et al. 2001) reported mean MMSE scores as an indicator of how early in the illness dementia was diagnosed.

3.2.5 Presentation of results

The papers included a wide range of settings, outcome measures and intervention type. Studies are divided by their clinical setting with the higher level of evidence presented first. Randomised controlled trials are generally considered to be the gold standard for assessment of any intervention so these are presented first, followed by non-equivalent group design studies and then studies which had a pre-post design.

3.2.5.1 Randomised controlled trials (RCTs)

Four studies reported results from RCTs (see Table 3-3). All were in a primary care setting with three studies trialling an educational intervention and the

remaining one testing the effect of specialist nurse assessment. Figure 3-2 and Figure 3-3 show unadjusted odds ratios for confirmed or suspected dementia.

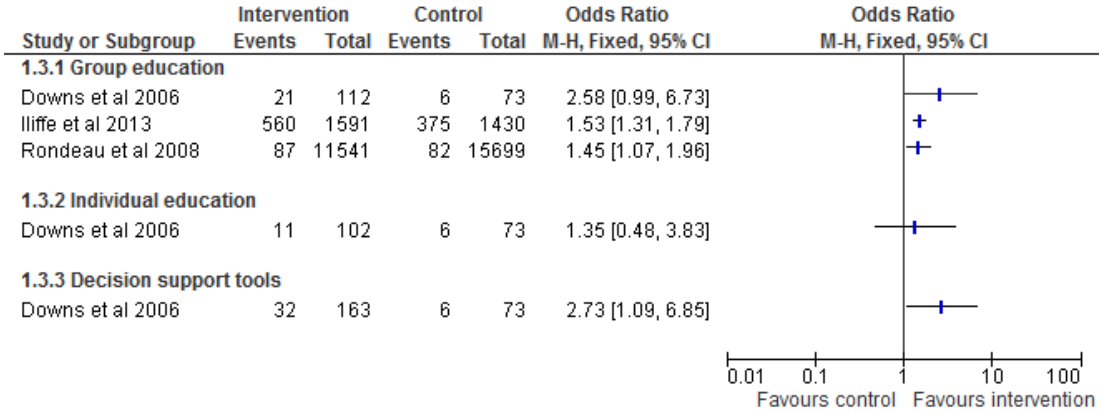

Figure 3-2: Odds ratios of GP suspecting dementia from RCTs

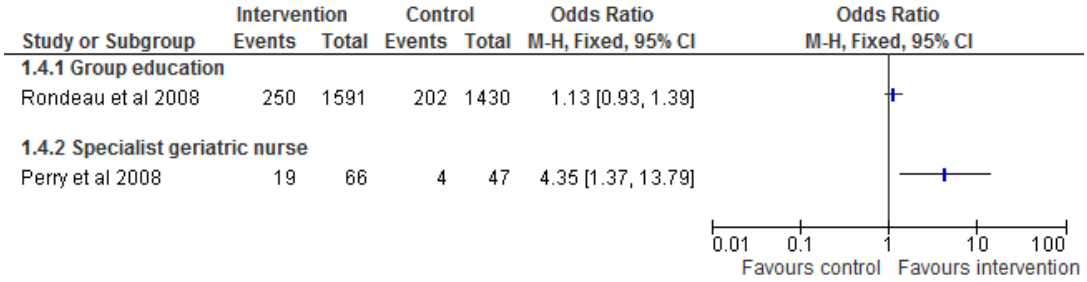

Figure 3-3: Odds ratios of a confirmed diagnosis of dementia from RCTs

Paper, Location	Quality score	Target of intervention	Patient population	Study duration	Intervention	Control group	Main outcomes
Downs et al 2006, UK	6	GP practices. 26 intervention practices, 10 control.	13068 registered patients aged ≥75 years. 450 records for people diagnosed with dementia	9 months after intervention	Each GP practice given: CD-Rom tutorial, decision support software or practice based workshops.	Standard GP care.	Higher percentage diagnosed with suspected dementia in decision support software practices (30% of total diagnoses, p=0.01) and practice based workshops (31% of total diagnoses, p=0.02) compared with control practices (11% of total diagnoses).
Iliffe et al 2013, UK	5	23 GP practices using electronic patient records – 11 intervention, 12 control.	Registered population 27240 - 11541 intervention, 15699 control.	12 months post-baseline.	Educational needs assessment then up to three face-to-face educational workshop sessions on dementia plus electronic resources that GPs could use during and after consultations with patients	Received summary of NICE-SCIE dementia guidelines	Case detection rates were unaffected by the intervention. Estimated incidence rate ratio (IRR) from multi-level Poisson regression modelling was 1.03, p value was 0.927 with 95% confidence interval 0.57 – 1.86
Perry et al 2008, Netherlands	6	Community dwelling people aged 70 or over referred by their GP to the programme.	151 patients - 85 intervention, 66 control.	9 months post-baseline.	Dutch Geriatric Intervention Programme (DGIP).	Usual care	151 participants, 38 had dementia at baseline. 23 new diagnoses of dementia, 19 in intervention group, 4 in control group. 9% new dementia diagnoses in control (n=4) vs. 29% in intervention groups (n=19)(p=0.02).
Rondeau et al 2008, France	8	684 GPs (23% of those approached) – 353 intervention, 331 control. Each had to include five consecutive patients.	3075 patients over age of 75yrs with new memory impairment enrolled, 3021 analysed – 1591 intervention, 1430 control.	October 2002 - February 2004.	Group educational meeting on dementia and training in the use of 4 neuro-psychological tests.	Usual GP care.	Two-fold higher rate of suspected dementia diagnosis in intervention group (OR1.99, p<0.0001) vs. control using random effects logistic regression. 82.4% of suspected dementia cases confirmed by specialist in intervention group vs. 70.8% in control group which gave an OR of 2.24 (p = 0.01) using adjusted regression.

Table 3-3: Randomised controlled trials of interventions to detect dementia

3.2.5.1.1 Educational interventions

In a cluster RCT, 684 GPs were randomised to either a two hour group educational intervention about dementia and using neuropsychological tests, delivered by neurologists, geriatricians or psychiatrists, or to no additional training. (Rondeau V. et al. 2008). Each GP was asked to recruit five consecutive patients aged 75+ with spontaneous memory complaints; 3021 patients were enrolled. Post-intervention, GPs in both groups judged if these patients had dementia, or not, or if the diagnosis was uncertain. Participants with suspected dementia were offered a referral for specialist assessment and this could also be requested by participants without suspected dementia or their families. 821 participants received a specialist assessment. Patients in the control group were older, less educated and from a lower social class than those in the intervention group. Compared with the control group, GPs in the intervention group were more likely to suspect dementia (36.4% vs. 26.8%, $p < .0001$) and less likely to report their patients did not have dementia (45.6% vs. 50.9%, $p = .004$) or to be uncertain about the diagnosis (18.0% vs. 22.3%, $p = .004$). Suspicion of dementia was two-fold higher for GPs in the intervention group (adjusted OR = 1.99, $p < 0.0001$). GPs from the intervention group also had a higher probability (adjusted OR = 2.24, $p = 0.01$) of correctly detecting demented patients. Around 40% of patients in intervention and control groups refused specialist assessment. Across the whole sample, around 15% of people were diagnosed with dementia by the specialist, and this did not differ between intervention and control groups (OR = 1.28, $p = 0.14$). Thus, while

GPs in the intervention group were more likely to accurately suspect dementia, the control group referred relatively more patients with uncertain diagnosis to specialists. Overall the intervention did not increase the number of diagnosed cases of dementia, but increased the number of GP suspected cases of dementia that were later confirmed by specialists and decreased the number of uncertain cases that were referred to specialists.

One study was an unblinded cluster RCT. GPs within the practices received either a CD-ROM tutorial (8 practices); decision support software (8 practices), workshops (10 practices); or no additional training (10 practices) (Downs et al. 2006). Practices in the workshop and CD-ROM tutorial groups cared for more care home residents than the other groups, but otherwise groups were similar. Before the intervention and nine months afterwards, the number of patients with dementia or probable dementia identified in practice electronic notes was compared between groups. Practices allocated to the group workshops and decisional support systems identified more patients with suspected dementia post-intervention, compared with the control practices, while there were no differences between the control and CD-ROM tutorial groups. There was no significant difference in mean diagnosis concordance scores, the primary outcome which assessed dementia diagnosis reliability, before or after the intervention, indicating diagnostic accuracy did not change.

One study compared usual care to an educational intervention comprising an educational needs assessment, group workshops on dementia and computer

support software, in an unblinded cluster RCT involving 23 practices (Iliffe et al. 2015). GP electronic notes were searched before and 12 months post-intervention for dementia or suspected dementia diagnoses. Compared with the usual care group, intervention practices had more patients with dementia diagnosed at baseline, more patients resident in care homes, a slightly higher mean list size and less deprivation. The proportion of patients aged over 65 diagnosed with dementia/suspected dementia did not differ in the intervention versus control practices post-intervention, taking into account the clustering and baseline dementia diagnosis rates (estimated IRR for the intervention compared with the usual care group from the multilevel Poisson regression modelling was 1.03; *p*-value=0.927; 95% CI 0.57 to 1.86).

3.2.5.1.2 Geriatric assessment and management programme

One study compared a Dutch in-home assessment and management programme for vulnerable adults to usual care. GPs referred 151 patients aged over 70 years, with a cognitive, mood, behaviour or mobility problem, who were randomised to usual care or the intervention (Perry et al. 2008). Baseline patient characteristics in each group appeared similar. The intervention comprised up to six home visits from a specialist geriatric nurse over three months, who completed a standard assessment, including cognitive assessment. Patient's notes were reviewed for dementia diagnoses or cognitive impairment by two researchers independently at baseline and 6 months post- intervention. Significantly more new dementia diagnoses were

made in the intervention versus control groups. Those diagnosed with dementia in the control group had lower MMSE scores than those in the intervention group but this was not quantified or tested statistically.

3.2.5.1.3 Summary of RCT evidence

- Two (Downs et al. 2006;Rondeau V. et al. 2008) out of three of RCTs of GP education found group educational interventions increased the likelihood that GPs would suspect dementia. The third (Iliffe et al. 2013), which did not find a positive result, was not powered to detect differences in proportions diagnosed with dementia.
- In the only study to validate the GP diagnosis with specialist assessment (Rondeau V. et al. 2008), GPs in the intervention group were more likely to suspect dementia cases that were later confirmed by a specialist, but as the control practices referred more patients with uncertain diagnosis, this did not change dementia detection rates.
- One study (Downs et al. 2006) assessed dementia diagnosis validity with a checklist and found it did not change, suggesting that the increase in cases detected is explained by an improvement in detection.
- The educational interventions involved GPs actively searching for people with cognitive complaints and pro-active specialist referrals, which is not usual clinical practice, and this may limit their implementation.

- One study found that multiple home visits by a specialist geriatric nurse increased dementia diagnoses compared to usual care.

3.2.5.2 *Non-randomised concurrent group design studies*

Four papers reported non-randomised concurrent group design studies (see Table 3-4). Two of these studies assessed changes in a specialist community clinic setting and two were set in primary care. Unadjusted odds ratios for obtaining dementia/suspected dementia diagnoses are shown in Figure 3-4.

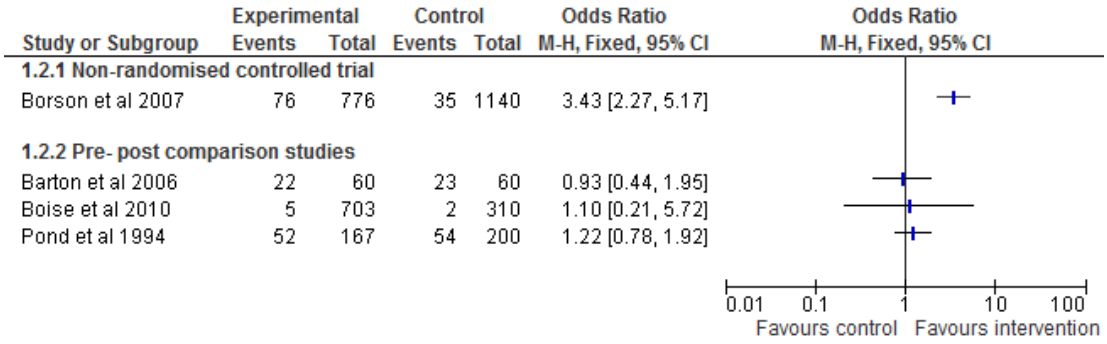

Figure 3-4: Odds ratios of obtaining a diagnosis of dementia/suspected dementia – non-randomised trials of educational interventions

Paper, Location	Quality score	Target of intervention	Patient population	Study duration	Intervention	Comparison group	Main outcomes
Banerjee et al 2007, UK	4	Older people in Croydon referred to specialist psychiatric services.	Over 46000 older adults in Croydon.	18 months data on consecutive referrals.	Croydon Memory Service established	Referrals to local old age community psychiatry service.	Consultant consensus used to estimate that 161 new cases of dementia diagnosed by the memory service. Increase of diagnosis rates of 63% (255 to 416 per year).
Borson et al 2007, USA	5	39 clinicians in 2 intervention and 2 control primary care clinics.	Patients over 65 years old. Intervention – 776 Control - 1140	Terminated early at 9 months (one clinic) and 3 months (one clinic).	Cognitive screening of all patients over 65 years with at least one appointment in trial period plus clinician education programme.	Routine care.	People diagnosed with dementia after a year in intervention group was 76/776. Control group diagnosis was 35/1140. Greater percentage of people diagnosed with dementia by non-geriatricians in intervention vs. control clinics at endpoint (F=4.87, P = 0.027, d.f.=1, 1553).
Chan et al 2010, UK	4	GP practices -14 intervention and 7 control practices.	No lower age limit. Intervention population 88924, control population 53863.	10 months after intervention.	Distribution of leaflets about memory problems to GP practices and community organisations	No leaflet campaign. Control locality had access to the same specialist services as the intervention locality.	Rate of recording of new cases rose by 29% in intervention locality and 64% in control locality.
Luce et al 2001, UK	7	Older people in Newcastle requiring specialist psychiatric services.	100 consecutive referrals to a memory clinic.	No timeframe specified.	Newcastle memory clinic (NMC) established.	100 consecutive referrals to traditional old age psychiatry services	Mean MMSE score (SD) 19.8(6.3) in NMC dementia patients vs. 14.0(7.4) in old age psychiatry patients with dementia, t=4.70, p<0.0001.

Table 3-4: Non-randomised concurrent comparison groups

3.2.5.2.1 Specialist community setting

Two studies compared traditional psychiatry services for older people with newly established memory services.

The non-randomised controlled trial with the highest validity score compared 100 consecutive referrals to traditional old age psychiatry services with 100 consecutive referrals to a newly founded memory clinic (Luce et al. 2001). A higher proportion of referred patients were diagnosed with dementia in the traditional service compared to the memory clinic (78% vs. 57%, $p<0.005$). More memory clinic patients were diagnosed with Mild Cognitive Impairment. The mean MMSE score was lower for the patients with dementia diagnosed by traditional services compared to those in the memory clinic (14.0(7.4) vs. 19.8(6.3); $t=-4.70$, $p<0.0001$) indicating that the memory clinic patients were probably diagnosed earlier.

Another group compared referrals over one year to old age psychiatry services with referrals over 18 months to the Croydon Memory Service(Banerjee et al. 2007). The memory service consultant psychiatrists decided by consensus whether the patients they had seen would have been referred to old age psychiatry services if the memory service was not established. From this, they estimated that 161 new diagnoses of dementia were attributable to the memory service activity, and thus the new service increased diagnoses by 63%

(95% CI 57% to 67%; from 255 to 416 referrals a year). They did not compare characteristics and degree of cognitive impairment between groups.

3.2.5.2.2 Primary care setting

One study evaluated a primary care worker education programme combined with a structured cognitive screening programme for people aged over 65 years (Borson et al. 2007). Method of allocation to intervention or control group was unclear and the intervention and control clinics differed in terms of staff type (geriatrician versus family doctor or general internist) and patient demographics. In the intervention group, medical assistants were trained to use the Mini-Cog (a cognitive screening tool); clinicians were informed about the study and options in response to positive cognitive screening. Control clinics received no additional support. All 776 patients over 65 who had at least one scheduled appointment during the 12 month study period were eligible for cognitive screening and were included in the analysis. Outcomes of interest were a recorded dementia diagnosis made using validated diagnostic manuals, referral to a dementia specialist and/or prescription of cholinesterase inhibitors. These outcomes (and the presence of any of these indicators, which was operationalized as suspected dementia) were compared between groups for the calendar year before and after the intervention.

The study was terminated early due to changes in the clinics. 70% of eligible patients were screened, 18% screened positive and there were no differences between screened and unscreened participants in terms of age, proportions

with a pre-existing dementia diagnosis, specialty referral, or anti-dementia medication prescription. The number of recorded dementia diagnoses increased over time in control and intervention clinics. There was a significant difference in the numbers of people diagnosed with dementia by non-geriatricians in the intervention compared to control clinics but no overall comparison in diagnosis rates was made. My odds ratio calculations indicated that the intervention had a significant effect on rates of suspected dementia diagnosis (OR = 3.43, 95% CI 2.27-5.17).

One study examined the impact of distributing leaflets about dementia to community centres and GP practices within a locality to a control locality (Chan et al. 2010). The intervention locality had an older population and higher baseline prevalence of dementia. The researchers searched GP records for any patients with a memory problem or dementia. The rate of recording of new dementia/memory problem diagnoses rose faster in the control compared to the intervention locality. Those with suspected dementia were more likely to be referred to secondary care in the intervention compared with the control locality (83.4% versus 78.4% (OR 1.29; 95% CI 0.99-1.93; p=0.044). They did not report any measures of diagnostic validity.

3.2.5.2.3 Summary

- There is further evidence from a non-randomised study that clinician education in primary care interventions can increase the proportion of people in whom GPs suspect dementia.
- There is preliminary evidence from one non-randomised trial that memory clinics provide a more timely diagnosis of dementia compared to standard psychiatric services. There is some evidence that memory clinics increase the number of people with dementia who are accurately diagnosed but firm conclusions are difficult due to the naturalistic study design used and the hypothetical judgments made in assessing cases.
- There is no evidence that an untargeted community leaflet campaign increased dementia diagnosis rates.

3.2.5.3 Pre- post- comparison studies

Five studies compared outcomes before and after an intervention (see Table 3-5). The majority of these were set in primary care, one was in a long-term care facility and one assessed specialist community services.

Paper, Location	Quality score	Target of intervention	Patient population	Study duration	Intervention	Comparison group	Main outcomes
Barton et al 2006, USA	6	Medical and nursing staff, no numbers given.	60 consecutive patients> 50 years old, staying at least 2 weeks in nursing home.	16 months for intervention. 13 months post-intervention.	Clinician education, decision support, nurse consultation	60 consecutively admitted patients after intervention.	23(38%) patients met criteria for cognitive impairment (CI) in the pre-intervention group and 22(37%) in the post-intervention group. This difference was not significant. Mean MMSE (SD) scores 18.4 (5.5) pre- and 16.3 (5.8) post-intervention, p=0.25.
Boise et al 2010, USA	4	18 clinicians and 26 medical assistants in one of 6 rural GP practices.	310 patients over 75 years seen pre-intervention.	3 month intervention. 4 months post-intervention.	Routine cognitive screening plus clinician education.	703 patients seen after the intervention.	Difference in recorded new diagnosis: Before -2 patients with dementia and 1 with MCI out of 310. After - 5/703 had dementia and 14/703 had MCI. Compared percentages before and after (grouped MCI with dementia – 2.7% vs. 0.97%, p=0.06).
Pond et al 1994, Australia	5	13 GPs.	Primary care patients over the age of 70 years. 200 patients pre-intervention.	6 months post-intervention.	Clinician education.	167 patients seen after the intervention.	Kappa for GP scores correlation with MMSE before intervention was 0.60 and after intervention was 0.44. P value for change in Kappa was 0.100. GP agreement with CIE/ICD-10 or DSM also not significant.
Ramakers et al 2011, Netherlands	6	Older people needing specialist intervention in Netherlands	All older people in Netherlands.	Retrospective analysis	Development of memory clinics (MCs) in Netherlands	Data from previous years.	Authors estimate 27% of incident dementia cases were identified in 2009 compared to 16% in 2004 and 5% in 1998.
Seabrooke and Milne 2009, UK	0	South Asian patients over the age of 65 years, from one GP practice.	167 patients	6 weeks for intervention.	Leaflets sent to South Asian patients then left in GP surgery.	Data on patient referrals from 3 month period prior to intervention.	Five Asian patients presented with memory problems within six week intervention period compared to none in the preceding 3 months.

Table 3-5: Pre- post- comparison groups

Key: GP = General Practitioner; MDT= Multidisciplinary team; MMSE = Mini-Mental State Examination; ICD-10 = International Classification of Disease version 10; DSM-IV = Diagnostic and Statistical Manual version IV; CEIs = Cholinesterase Inhibitors; NICE-SCIE = The National Institute for Health and Clinical Excellence (**NICE**) and the Social Care Institute for Excellence (**SCIE**); CAMCOG = Cambridge Cognitive Examination; OR = Odds Ratio; CIE= Canberra Interview for Elderly

3.2.5.3.1 Primary care setting

Pond et al (Pond et al. 1994) tested the effect of an interactive one-to-one session with a fellow GP about dementia. Thirteen GPs saw 200 patients over the age of 70 before the intervention and 167 patients in the 6 months afterwards. GPs judged whether the patients had dementia. All patients were assessed by a researcher using the MMSE and Canberra Interview for the Elderly (CIE), which generates dementia diagnoses from valid diagnostic manuals. GP judgements were compared with the MMSE and CIE scores. Baseline agreement between the GPs opinions and CIE scores were reasonable (Kappa score=0.35) and did not improve significantly after the intervention (Kappa = 0.48, p=0.212) indicating that dementia diagnostic accuracy did not improve.

One study evaluated a cognitive screening programme plus clinician education in 6 rural primary care practices (Boise et al. 2010). In the 3 month trial period, all patients over 75 who had an appointment with a clinician were eligible for screening. Clinical work-ups on all those who screened positive were checked in the 2 months after the intervention. Around half of those who screened positive had a specialist memory evaluation. The authors compared the percentages of those diagnosed with dementia or Mild Cognitive Impairment before and after the intervention and found no significant difference.

Another study reported on a pilot study evaluating a leaflet campaign (Seabrooke V. & Milne A. 2009). A bilingual (Punjabi/English) leaflet about memory problems was sent to 167 South Asian patients without a known dementia diagnosis, together with an invitation to see a nurse practitioner in the next 6 weeks if they had memory-related concerns. The nurse was trained in dementia recognition and management. Five Asian patients presented with memory related concerns in the six week research period, compared with none in the preceding three months. Diagnoses were not reported.

3.2.5.3.2 Specialist community setting

One study involved sending out questionnaires to all Dutch hospital based memory clinics in 1998, 2004 and 2009 (Ramakers & Verhey 2011). Response rates were 88% in 1998, 93% in 2004 and 78% in 2009. The number of memory clinics increased from 12 in 1998 to 43 in 2004 and 63 in 2009. The average number of newly referred patients per clinic increased from 130 in 1998, to 199 in 2004 and 225 in 2009. The authors estimated that 27% of all incident dementia cases in the Netherlands were identified in 2009 compared with 16% in 2004 and 5% in 1998.

3.2.5.3.3 Long-term care facility setting

One study evaluated an intervention comprising clinician education, decision support tools and consultations with a memory clinic nurse practitioner (Barton et al. 2006). Numbers of documented diagnoses of dementia or cognitive

impairment were compared in 60 consecutive patients aged > 50 years old admitted to a nursing home for at least two weeks, before and after the intervention. The number of cases of suspected dementia recorded did not change significantly. However, dementia subtype was more likely to be identified post-intervention (91% vs. 52%, p<007), and a dementia management plan by a doctor (90% vs. 35%, p<0.001) or other care provider (62% vs. 22%, p = 0.013) was more likely to be recorded.

3.2.5.3.4 Summary

- No positive effects were found for individual clinician training, group training with a routine screening programme or a targeted leaflet campaign. Increasing the number of memory clinics correlated with an increased number of dementia diagnoses.

3.3 Discussion

This was the first systematic review to identify studies across all clinical settings that might have an impact on dementia diagnosis rates, accuracy or stage of diagnosis.

I found good evidence from RCTs that GPs attending group education sessions more frequently suspect dementia, but evidence about the impact of these interventions on diagnostic validity, and thus whether they truly increase dementia detection, was limited. GP education did not increase the number of

confirmed dementia diagnoses, but did increase the number of cases that were recognised as possible dementia by GPs prior to specialist assessment.

There was some evidence that decisional support systems increased dementia diagnoses, indicating that more active prompts in clinical practice may be useful. There was one RCT which found that up to 6 visits by a specialist geriatric nurse increased dementia diagnoses. There was no evidence that interventions targeting the whole community, through a community leaflet campaign, increased dementia diagnosis rates, although these have not been evaluated in RCTs.

Adequate dementia diagnostic services are a prerequisite for enabling more people with dementia to be diagnosed. Memory services have been introduced throughout the UK and elsewhere to try to improve dementia detection but it is difficult to assess their impact in a rigorous way using an RCT. I found evidence that these services may lead to dementia being diagnosed earlier, but weak evidence about whether they improve overall detection rates. However, one study found that the number of memory services was correlated with the numbers of people diagnosed and the percentage detection rate.

Most of the studies focused on educating primary care professionals, and few were aimed at the general older population. Untargeted leaflet campaigns did not improve diagnostic rates in one, low validity study but RCTs are needed.

3.4 Conclusions

Lack of evidence of efficacy is not evidence of inefficacy, and the most striking finding was a paucity of evidence about interventions to improve the detection of dementia. Based on this review, the combination of education of primary care practitioners about dementia detection, and establishing specialist memory assessment services currently have the best but still very limited evidence for increasing detection of dementia at the earliest stage in the illness. There is limited and doubtful evidence about the efficacy of either of these and new strategies may be necessary.

3.5 Relevance to the development of my intervention

Most of the studies assessed interventions situated within the healthcare system. These provided a useful insight into the fact that even when people seek help for memory problems, there may be factors within the healthcare system that prevent them from getting a diagnosis but did not provide principles to help me design my own intervention, as targeting the healthcare system would have been beyond the scope of this project. In this review I found two leaflet interventions aimed at empowering patients. The first showed that an untargeted leaflet left in community centres and GP practices did not increase help-seeking behaviour. The second showed that a leaflet targeted at the South Asian population and sent from primary care may have increased the numbers of South Asian people seeking help for memory problems. This suggested that designing a culturally targeted intervention and having it sent

to patients from their GP practice could potentially affect help-seeking for memory problems.

3.6 Update on literature search

Since carrying out my systematic review for this thesis, there have been three further studies of interventions to increase dementia diagnosis, of which one study was informed by my project and on which I was a collaborator.

3.6.1.1 Education of health professionals about dementia

The first study was based in the US and involved general practitioners and affiliated staff members taking part in a one day training course on dementia screening, diagnosis and management including information about and communication with local community dementia service providers (Lathren et al. 2013). Participants completed questionnaires about their confidence in diagnosing dementia and their use of cognitive screening tools at baseline, immediately after training and after 6 months. There was an increase in the use of cognitive screening tools and physicians reported an increase in their competence in diagnosing and managing dementia. There were more referrals to community services in the two years after the intervention compared to the period before. However, there was no control group and no data on the number of confirmed diagnoses of dementia before or after the intervention so it does not add to literature regarding dementia diagnosis although we could assume,

like other GP training interventions, that it might increase referrals to specialist services but not confirmed diagnoses.

3.6.1.2 Empowering patients (whole population)

The second study was a UK-based cluster randomised controlled trial of a leaflet about dementia which was designed with input from the Alzheimer's Society, healthcare professionals, people with mild cognitive impairment and family carers of people with dementia. GP practices in and around London were randomised to receive either the intervention or treatment as usual. The leaflet was then sent with a personal letter from a GP to all people over the age of 70 without a known diagnosis of dementia who were registered to intervention practices. Independent researchers collected masked data on referrals from included GP practices to local memory services and data on GP consultations about memory concerns (Livingston et al. 2017). GP consultations with patients with suspected memory disorders increased in intervention versus control group (odds ratio = 1.41; 95% Confidence Intervals = 1.28, 1.54) but there was no between group difference in the proportions of patients referred to memory clinics (166, 2.5%; 220, 2.7%; P= .077 respectively). Cognitive severity at diagnosis in the memory services was no different in the intervention versus control groups (99 intervention, mean MMSE = 22.04, 95% Confidence Intervals = 20.95 to 23.13; 124 control, mean MMSE = 22.59, 95% Confidence Intervals = 21.58 to 23.6; P= 0.48). The study showed that this intervention increased the numbers of people seeking help

from their GPs for memory problems but there was no concomitant increase in referrals to memory services or decrease in severity of cognitive decline amongst those referred to memory clinics so no increase in timely diagnosis. Also, there was no way of assessing if those who consulted their GPs had any evidence of objective cognitive impairment and therefore should have been referred for specialist assessment.

3.6.1.3 Empowering patients (Black community)

The third study was part of the Collaborations for Leadership in Applied Health Research and Care (CLAHRCs), which are initiatives funded by the National Institute for Health Research to undertake applied health research and support the translation of research evidence into practice in the NHS. The funding was based on my study but in a different group and was awarded to Professor Gill Livingston in 2014 to carry out a program of work aimed at encouraging earlier help-seeking for dementia among Black people in and around London. I was a collaborator on the project and primary supervisor of an MSc student (Moise Roche) who carried out the recruitment and interviewing of participants.

The study involved designing and testing, in a pilot RCT, an intervention to improve attitudes to help-seeking for dementia among people from Black ethnic backgrounds. The intervention was a leaflet which included information about dementia and addressed concerns that participants in focus groups had raised about help-seeking from a GP about memory problems. The main

outcomes of interest were feasibility and acceptability and these outcomes were met. Additionally, like in my study, participants completed the Dementia Knowledge Questionnaire and a questionnaire about attitudes to help-seeking for dementia. There were no differences between the two groups on these measures but the study was not powered to detect these (Roche et al. 2017). This study provided further evidence that it is possible to recruit from primary care, that such interventions are acceptable and it is possible to follow up participants. Most people in this study looked at the intervention but it is unclear whether the leaflet will be trialled in a definitive randomised controlled trial or whether, like mine, the intervention might be better disseminated through other means.

3.6.1.4 Summary of interventions to increase diagnosis of dementia

My systematic review showed that GP training increased the numbers of suspected dementia diagnoses but not the numbers of confirmed diagnoses. The newer studies I found add to this evidence and also suggest that informing patients and empowering them to seek help does increase help-seeking from GPs but this does not lead to more onward referrals. Help-seeking for cognitive complaints and subsequent diagnosis is a complex and multi-stage process so it may be that efforts are needed at both empowering patients and training GPs while strengthening links with local memory services, in order to have an impact on diagnosis rates or timely diagnosis.

As outlined earlier, the search for my systematic review revealed a number of local initiatives aimed at raising awareness of dementia. I contacted all organisations involved in such work to find out if they had any data on the impact of their work.

3.7 Awareness campaigns

The National Dementia Awareness campaign in the UK was launched in September 2012 (http://www.dh.gov.uk/health/2011/09/raising-dementia-awareness). This involved TV adverts, online resources and development of an information leaflet. I found information online about awareness campaigns being run at a local level, for example in Nottingham (http://www.nottingham.ac.uk/impactcampaign/campaignpriorities/healthandwell-being/dementia/dementia.aspx) and the South West (http://www.dementiaawareness.co.uk/). These are all for the general population but a campaign specifically aimed at the South Asian population has been on-going in Bradford since 2009 (http://www.meriyaadain.co.uk). The latter is a social services led initiative that carries out community road shows, radio programmes and hosts groups to raise awareness of dementia and improve access to dementia services amongst this ethnic group. Internationally, there are multiple awareness campaigns in different countries aimed at reducing the stigma associated with dementia using a variety of techniques such as providing information, hosting social events and facilitating

the involvement in the arts for people with dementia (Batsch N.L. and Mittelman M.S. 2012).

All of these initiatives seem to be a rational approach to raising awareness and reducing stigma and are described by people involved with them in very positive terms but there was no data available on their effect on outcomes such as attitudes to help-seeking for dementia or actual help-seeking behaviour. I therefore decided to carry out a study to see if I could find a temporal association between the launch of the UK's National Dementia Strategy, and diagnosis rates of dementia. This is described in the next chapter.

4 : An observational study of dementia diagnosis trends over time

In this chapter I describe an observational study I carried out to explore the temporal links between the launch of the National Dementia Strategy in England and dementia diagnosis rates. A copy of the published paper is in Appendix 2.

Although a policy-level intervention such as the National Dementia Strategy was beyond the scope of my own intervention, I wanted to explore whether such a policy could have an impact on dementia diagnosis. This was to examine the context in which my own intervention would be designed and also to gain insights into how policy could affect dementia diagnosis. I reasoned that the mechanisms of any changes might provide strategies to inform development of my own intervention.

4.1 The National Dementia Strategy

The National Dementia Strategy (Department of Health 2009) was launched in February 2009 in the UK. Its main aims were to increase awareness about dementia, improve rates of diagnosis and improve the quality of care that people with dementia receive. Additional funding of £150 million was provided to Primary Care Trusts in order to improve diagnosis rates, primarily through increasing access to diagnostic services.

4.2 Assessing the trends of dementia diagnosis over time

To explore whether the National Dementia Strategy was linked to improved diagnosis rates, I led an analysis of routinely collected and available data, to see if there was an association between launch of the National Dementia strategy and changes in dementia diagnosis rates.

4.3 Objectives

- To assess whether the implementation of National Dementia Strategy (NDS) was associated with an increase in the rate of identification of people with dementia.
- To assess whether the NDS was associated with an increase in the treatment of dementia with anti-dementia medications.
- To consider the validity of dementia diagnoses on primary care registers.

4.4 Methods

4.4.1 Available data

The following figures were available from national databases and the Alzheimer's Society Mapping the Dementia Gap publications:

- Annual national community-level prescribing data from 2003 to 2012 (calendar year) (Health and Social Care Information Centre 2013c).

- National hospital-level prescribing data from 2007 to 2011(calendar year) (Health and Social Care Information Centre 2013a).
- Yearly prescribing data of anti-dementia medications at Primary Care Trust (PCT; an administrative body covering local primary care practices) level for 2008/09 to 2011/12 (fiscal year – April to March) (Health and Social Care Information Centre 2013b).
- Number of people diagnosed with dementia on General Practitioner (GP) databases by PCT from 2006/07 to 2011/12(these are recorded by GP practice as Quality and Outcomes Framework (QOF) data, fiscal year) (Health and Social Care Information Centre 2013e).
- Estimated true number of people with dementia in each PCT from 2010 to 2012 (Alzheimer's society 2012;Alzheimer's society 2013).

4.4.2 Dementia diagnosis rates

The dementia diagnosis rates were calculated by dividing the numbers of GP recorded dementia diagnoses (from QOF registers) by the estimated total number of people with dementia. I used the estimates in the Alzheimer's Society reports of the actual prevalence of dementia in each PCT for 2010-2012. I calculated the prevalence of dementia for preceding years using the same method used by the Alzheimer’s Society in their reports (Alzheimer's society 2012;Alzheimer's society 2013).

4.4.3 Validating dementia diagnoses

As QOF data relies on GPs to enter dementia diagnosis onto their database, I wished to establish its validity, by comparison with an independent method of estimating the rate of dementia diagnosis i.e. with prescription levels for anti-dementia drugs calculated by:

- Net Ingredient Cost (NIC): the cost of the drug before discounts which does not include any dispensing costs or fees.
- Items dispensed: A prescription item refers to a single drug on a prescription so if a prescription form includes three medicines it is counted as three prescription items (Health and Social Care Information Centre 2013d).The potential disadvantage of relying on this method of calculating costs is that regional or temporal differences in prescribing policy may exist e.g. prescribing for a maximum of one month versus prescribing for a maximum of three months at a time, which could affect results significantly.

I used community NIC as hospital NIC data was only available from 2007, was a relatively small figure (approximately 10% of total) and changed over time at around the same rate. I adjusted the NIC for inflation as specified by the Bank of England inflation calculator (Bank of England 2013) to enable me to consider whether there were true differences between years. I correlated NIC and number of items dispensed to see if they were similar. The correlation in

2008/9 between the two was 0.974, in 2009/10 was 0.968, 2010/11 was 0.965 and in 2011/12 was 0.963 (all p values <0.001) so I concluded that they were very similar. I therefore report only NIC (as it would theoretically be less prone to variation over time and between districts) until 2012 when cholinesterase inhibitors came off license as follows: Donepezil, Feb 2012; Galantamine, Jan 2012; Rivastigmine, July 2012 (Health and Social Care Information Centre 2013a).

4.4.4 Statistical analysis

Numerical data were summarised using mean and standard deviation or median and range depending on data distribution. I used Spearman rank correlation to assess the association between two numerical variables.

4.4.4.1 Dementia diagnosis rates

I used negative binomial regression (NBR) models to assess trend in diagnosis rates before and after NDS, adjusting for cluster at PCT level. The NBR model is appropriate for count data and is similar to the Poisson regression model but is more appropriate in the presence of over dispersion (Gardner W. et al. 1995). The NBR yield estimates of incidence rate ratio (IRR) and 95% confidence intervals (CI), where an IRR value of 1 indicates no impact on diagnosis rates. I used total population at risk as the offset variable in order to adjust for variable population denominators.

4.4.4.2 Dementia drug prescriptions

I used Negative Binomial Regression to assess the trend in number of dementia drug prescriptions, before and after the NDS, adjusting for cluster at PCT level with the total number of prescriptions as the offset variable.

I used multilevel linear regression to examine the effect of NDS on the relative prescription cost, adjusting for cluster at PCT level (Snijders T.A.B. and Bosker R.J. 1999). I used residual plots to investigate assumptions of normality of residuals required by the multilevel models.

4.4.4.3 Validity of QOF figures

In order to explore whether areas with a calculated low diagnosis rate were explained by lack of recording of dementia diagnoses on the QOF registers, I assessed the relationship between dementia diagnosis rate and NIC costs per person diagnosed with dementia. If there was a bias in reporting then the mean NIC costs per person diagnosed with dementia would be higher than in other areas. I categorised diagnosis data and prescription data into quartiles and then assessed the Spearman correlation between them.

All models are fitted with year as fixed effect. Descriptive analyses were carried out in SPSS Version 20. All models were fitted in Stata Version 12.

4.5 Results

4.5.1 Dementia diagnosis numbers and percentages

The number of people with a dementia diagnosis in England appeared to be similar from 2006 to 2008 but increased every year after 2008. This is shown in Figure 4-1.

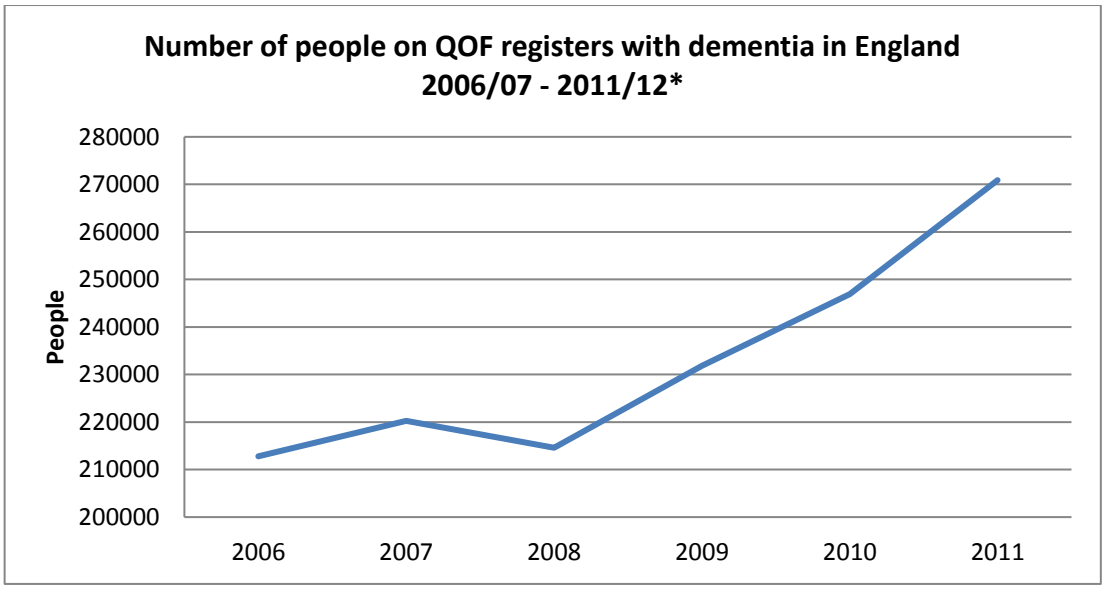

Figure 4-1: English National diagnosis numbers, 2006/2007 to 2011/2012.

QOF = Quality Outcomes Framework which is data on recorded diagnoses in GP practices

4.5.2 Dementia diagnosis rates

Table 4-1 shows the median number of recorded dementia diagnoses per PCT, the mean proportion of dementia diagnosed per PCT and change in mean number diagnosed per PCT compared to the previous year, from 2006 to 2012.

Regression analysis showed that dementia diagnosis rates were lower in 2006-2008 compared to 2009, as shown in Table 4-2. The dementia diagnosis rate increased by an estimated 4% in 2010 (IRR 1.04, 95% CI 1.03-1.05) and 12% in 2011 (IRR 1.12, 95% CI 1.11-1.13) compared to 2009.

Year	2006/7	2007/8	2008/9	2009/10	2010/11	2011/12
Median number (range) diagnosed with dementia per PCT	1088 (319-6763	1141.5 (313-7109)	1114 (310-7047)	1186.5 (353-7527)	1286.5 (399-7765)	1419 (448-8058)
Mean dementia diagnosis percentage (Standard Deviation) per PCT	36.54(5.6)	37.10(5.8)	35.85(5.8)	38.27(6.1)	40.32(6.4)	42.29(6.8)
Mean increase in numbers diagnosed with dementia per PCT (Standard Deviation) compared to previous year	N/A	48.7 (58.6)	-37.5 (55.8)	111.6 (100.1)	99.2 (75.1)	158.5 (107.7)

Table 4-1: Numbers and percentages of people diagnosed with dementia per Primary Care Trusts (PCT) per year

	Dementia diagnosis		Numbers of anti-dementia drug prescriptions		Cost of anti-dementia drugs compared with overall spending	
Year	**Estimate[1] (95% confidence interval)**	**P value**	**Estimate[2] (95% confidence interval)**	**P value**	**Estimate[3](95% confidence interval)**	**P value**
Years		**<0.001**		**<0.001**		**<0.001**
2006	0.96 (0.53 to 0.97)		No data available		No data available	
2007	0.98 (0.97 to 0.98)		No data available		No data available	
2008	0.94 (0.93 to 0.95)		0.88 (0.84 to 0.92)		-0.95 (-1.13 to -0.68)	
2009	**Reference year**					
2010	1.04 (1.03 to 1.05)		1.11 (1.06 to 1.16)		0.54 (0.27 to 0.81)	
2011	1.12 (1.11 to 1.13)		1.24 (1.19 to 1.29)		2.26 (1.99 to 2.53)	

Table 4-2: Results of regression analyses for dementia diagnosis and anti-dementia drug prescriptions

[1]Estimates represent incidence rate ratio (IRR) of dementia diagnosis relative to year 2009 obtained from Negative Binomial Regression, offset against population at risk

[2]Estimates represent incidence rate ratio (IRR) of number of anti-dementia drug prescriptions relative to year 2009 obtained from Negative Binomial Regression, offset against total number of prescriptions

[3]Estimates represent the mean difference in relative cost of dementia drug obtained by multilevel linear regression compared to 2009

4.5.3 Validity of QOF dementia diagnosis data

Dementia diagnosis rates were highly correlated with both numbers of anti-dementia medications dispensed and cost of prescriptions (see Table 4-3) indicating validity.

Year	Correlation of dementia diagnosis against items dispensed	P value	Correlation of dementia diagnosis against NIC*	P value
2008/09	0.58	<0.001	0.61	<0.001
2009/10	0.57	<0.001	0.61	<0.001
2010/11	0.57	<0.001	0.62	<0.001
2011/12	0.56	<0.001	0.61	<0.001

Table 4-3:Spearman's rank correlation between numbers of people with dementia diagnoses on Primary Care Trust (PCT) Quality Outcome Framework register with PCT level prescription data
*NIC=Net Ingredient Cost

4.5.4 Anti-dementia drug prescriptions

Rate of prescriptions of anti-dementia drugs has increased dramatically since 2010 (see Figure 4-2).

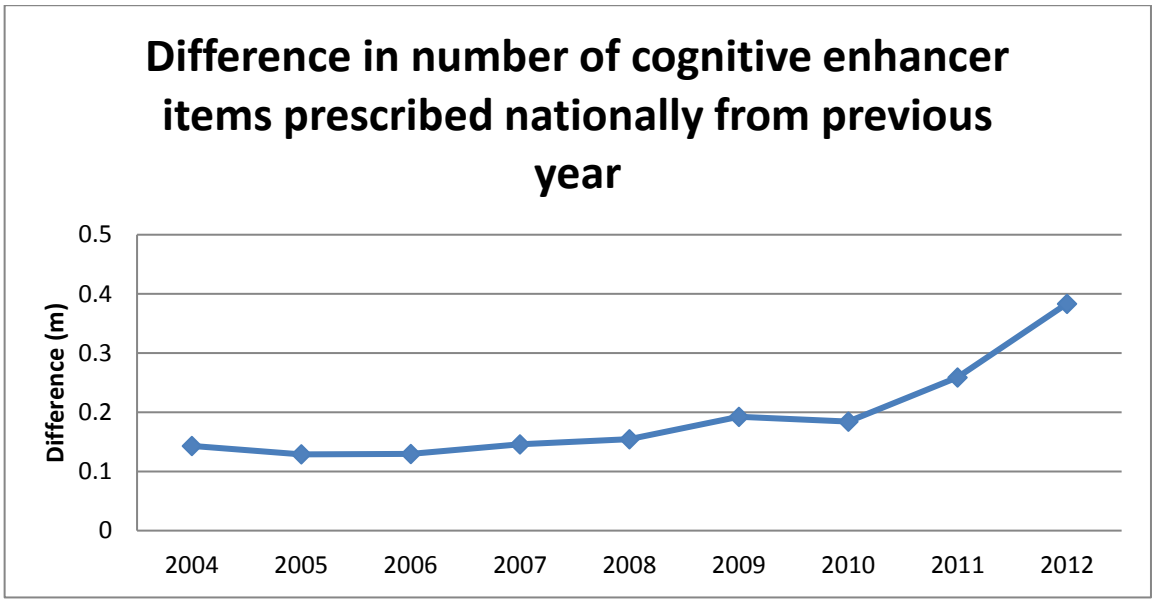

Figure 4-2: Rate of increase in cognitive enhancer prescriptions over time.

Regression analysis showed that the numbers of anti-dementia drug prescriptions increased significantly after 2009. The cost of anti-dementia drugs relative to total PCT prescriptions costs also increased significantly after 2009. All of these results are shown in Table 4-2.

4.6 Discussion

Overall these results indicate that launch of the National Dementia Strategy (NDS) is temporally linked to an increase in diagnosis rates and in prescriptions of anti-dementia medications in England. I found that mean number of dementia diagnoses per PCT per year, (as reflected in GP recording of the diagnosis on their QOF register), and dementia diagnosis rate increased

from the year the NDS was launched. Prior to this there was no clear increase in number of diagnoses since records began in 2006/07; therefore the change does not seem to be just a continuation of a trend that was already occurring or established.

There was a larger increase in anti-dementia medications prescribed in 2010, the year after the NDS was launched. The costs of anti-dementia medications as a proportion of overall spending in PCTs also significantly increased following launch of the NDS.

The mechanism of this change in diagnostic rates and prescriptions is unclear. The NDS involved provision of additional funding to PCTs. A government review of how this was spent found that less than half of PCTs responded to the survey, of which two-thirds were unable to say where they had allocated the money. Those who could comment on spending mostly prioritised funding memory services and early diagnosis (All-Party Parliamentary Group on Dementia 2010). It is unlikely that those who were unable to say where it was spent used it for dementia and thus it appears that most of the funding was not used for the intended purpose. Therefore increased spending seems unlikely to be the sole mechanism of change.

The other two elements of the NDS were national dementia awareness campaigns and addressing the quality of dementia care partly through the establishment of memory clinics. A memory clinic survey with an 80%

response rate found that the number of people using memory services in each PCT was 1.5 times higher in 2010/11 than in 2008/9 (The NHS Information Centre 2011). In England, consistent with NICE guidelines, most GPs do not diagnose dementia and initiate medication. An increase in diagnosis rates therefore indicates an increase in specialists' diagnoses, probably in memory clinics as they are now the assessment and diagnosis route in most services for people with suspected dementia. This accords with previous reports of an increase in numbers diagnosed with dementia with the establishment of memory clinics (Ramakers & Verhey 2011). Nationally and internationally re-labelling mental health services as "memory clinics" may also reduce the barrier to diagnosis caused by the stigma of attending mental health services (Mukadam N. and Livingston G 2012).

It may also be that GPs' and the public's opinion about obtaining a dementia diagnosis has changed with the national awareness campaigns, meaning GPs are more willing to suggest the possibility of the diagnosis and refer patients who are more willing to have further assessment, but I was unable to find evidence about opinion stability or change.

Another explanation for the increase in both diagnosis rates and prescriptions of anti-dementia medications could be the National Institute for Health and Care Excellence (NICE) guideline amendment in August 2009 to allow prescription of cholinesterase inhibitors for mild dementia, whereas previously only people with dementia of moderate severity were eligible for this treatment.

This change would have made many more people eligible for medication and could also have motivated clinicians to diagnose dementia more.

Overall, this analysis suggests that it is possible to improve diagnosis rates through national campaigns and policy-level interventions such as the National Dementia Strategy but a causal link cannot be established.

4.7 Relevance to the development of my intervention

Although there is evidence that dementia diagnosis rates and prescription of anti-dementia medication increased overall after launch of the National Dementia Strategy, I could find no data on diagnosis rates in different ethnic groups. The mechanism of change is also uncertain, although if it is through increasing access to memory services then the potential to benefit people from minority ethnic groups will depend on patients coming forward with symptoms. This makes the encouragement of help-seeking, for minority ethnic groups, through interventions such as my own seem even more relevant. The study also highlights the importance of considering all ethnic groups when bringing about national policy changes.

4.8 Other observational studies

A more recent, similar study assessed recorded diagnoses of dementia and the prescription of anti-dementia medications from 2005 to 2015 using data from the Clinical Practice Research Datalink which uses data from GP

practices (Donegan et al. 2017). The authors found that in the 10 year period they surveyed, diagnosis rates doubled and the proportion of people diagnosed with dementia who were prescribed cholinesterase inhibitors more than doubled from 15 to 36%. They attribute the increase in diagnosis and prescribing to the National Dementia Strategy and highlight how policy can have an impact on care for dementia. The possible mechanisms for this change include increasing services available and improving public awareness, tackling stigma, giving people and professionals hope and providing incentives to GPs for establishing dementia registers, although it is not possible to confirm these pathways. These findings, using different data to the ones I used, validate my own findings and indicate that the National Dementia Strategy did result in an increase in dementia diagnosis rates and prescriptions of anti-dementia medications.

4.9 Summary

In chapter 3 I have shown how interventions targeted at healthcare professionals show promise in increasing the numbers of people with suspected dementia diagnoses. Providing patients with information about help-seeking empowers them to seek help. In this chapter I have described observational studies which have shown that national, untargeted policies are linked with increases in dementia diagnosis, possibly through reducing stigma and increasing availability of specialist assessment. Timely diagnosis of dementia is important for all but my searches found no trials of interventions

targeted specifically at people from minority ethnic groups. I carried out qualitative work in order to design an intervention targeted at the South Asian population. This is described in the next two chapters.

5 : Qualitative study methods

This chapter describes qualitative work that I carried out to explore barriers to help-seeking for dementia in a sample of community-dwelling South Asian participants. I sought to find out what factors might encourage earlier help-seeking in this group This qualitative paper was published in BMJ Open in September 2015 and a copy of the paper can be found in Appendix 3.

5.1 Reason for doing the study

Equal access to dementia services for all ethnic groups is important to ensure access to potential health benefits (see section 2.3). Barriers to accessing dementia services have been described in a broad range of Black and Minority Ethnic groups including attributing the symptoms to normal ageing or other physical, spiritual or psychological causes; denial that there was a problem or normalisation of symptoms; concerns about stigma related to dementia; perceived ethical imperative to care for one's own family members without accessing help; negative experiences of the healthcare service and feeling there was nothing that could be done for dementia. The only facilitator to help-seeking found was knowledge about dementia (Mukadam et al. 2011b). A diagnosis itself was less valued among BME carers than their White UK counterparts (Mukadam et al. 2011a).

Barriers to help-seeking for dementia seem culture-specific, therefore interventions to alter help-seeking behaviour should also be targeted at

specific barriers, as provision of information alone is not enough to alter health-related behaviours (Kelly and Barker 2016;Robertson R. 2008).

5.2 Ethics

I obtained approval from the National Research Ethics Service (NRES) committee Fulham for this study and the pilot randomised controlled trial. Due to initial difficulties in recruiting participants, I modified the protocol for the study so that participants were reimbursed for their time with high street vouchers. The ethics committee approved this amendment. A copy of the ethics approval letters are in Appendix 12.

5.3 Participants

I defined South Asian as being anyone who identified themselves as having South Asian identity or heritage by links to any South Asian country, primarily India, Pakistan, Bangladesh, Nepal and Sri Lanka.

I searched for South Asian community organisations in London using online search engines and contacted organisational leads by telephone or email to explain what I was doing and to ask permission to conduct the study in their organisation. Participants were reimbursed for their time with high street vouchers.

I purposively recruited participants from South Asian community centres and then through snowballing from those contacts and researchers' personal or

professional contacts, in order to gain a maximum variation sample and therefore range of opinions. I used snowballing in order to try and recruit people who were not active within South Asian community groups. I wished to include any adult who identified themselves as being South Asian, aiming for participants from either gender, a range of marital status, ages, educational background and occupations; people born in UK and a variety of South Asian countries, and from differing religions. I recruited participants who wished to be in a single-sex only group and those who were comfortable in a mixed sex group. I wished to explore the views of as many different people within the South Asian community as possible and included participants with and without experience of caring for or interacting with people with dementia. I did not wish to exclude those who may have a diagnosis of dementia themselves as long as they had capacity to consent to take part in the study.

I chose to focus on people from South Asian backgrounds who spoke either English or Bengali. This minimised the need for interpreters, in order to reduce costs. I chose Bengali as this is one of the most commonly spoken South Asian languages in the UK (Office for National Statistics 2013).

My preferred format of discussion was a focus group as it allows the interactions between participants to help identify group norms, highlights the framework of understanding and can encourage open conversation about sensitive topics (Kitzinger 1994). However, I also realised that some people may find group settings difficult and individual interviews can also provide a

more in-depth understanding of the factors that underpin participants' responses (Ritchie et al. 2013). Where possible I conducted focus groups with a colleague, but if less than three people attended organised sessions, or if participants expressed a preference for an individual interview, I carried out individual interviews. Some focus groups were facilitated with other researchers involved in the study (CC, GL, AW, NK). Interpreters were used unless all participants were fluent in English.

5.4 Procedures

5.4.1 Information sheet and consent

All participants were given a Participant Information Sheet to read at the start of the session or prior to it, via post or email. Any questions about the information sheet were answered by one of the researchers and then participants were asked to sign a consent form if they wished to take part in the study. Copies of the information sheet and consent form are in Appendix 4 and 5.

Consenting participants were asked for demographic information.

5.4.2 Focus group process

We began the focus groups or individual interview by showing participants, and reading to them, a short case vignette about a 70 year old South Asian lady with memory problems, which several memory clinic psychiatrists agreed

suggested significant memory problems justifying further investigation for the possibility of dementia. This vignette is shown in Box 5-1.

Imagine that Mrs Chaudry is a 70 year old close relative of yours. Family members have noted that she is more forgetful lately. She cannot remember conversations with people and forgets appointments with her doctor. She often misplaces important items like her keys and glasses. She is physically healthy but is concerned about her memory.

Box 5-1: Vignette for focus groups

Discussion was opened by asking participants what problem they thought the lady in the vignette had and what she should do about it. I chose to use a vignette as they are useful in qualitative research to clarify people's judgement, provide a less threatening way of exploring potentially sensitive subjects and can act as a useful way to open group discussion (Barter and Renold 1999). I also wished to use the vignette to specify the severity of the memory problems we would be discussing to get a better understanding of how these in particular would be viewed.

Using a series of interview prompts, discussion was guided along to participants' experiences of memory problems, whether they would seek help if they had problems similar to the woman in the vignette and what would encourage help-seeking at an earlier stage for memory problems. The topic

guide was reviewed after each focus group and modified if needed. The topic guide is shown in Box 5-2.

Box 5-2: Focus group/interview script and questions

Introduction of researchers: Thanks….*We are researchers from University College London. We will be recording this group. Everything you say is confidential but we would like you to introduce yourselves for the recording so that the typist can identify you. Our names are...*

Description of research topic: *We are interested in how people from the South Asian population, in particular, think about memory problems as they get older and what you think might be helpful.*

You have just read about Mrs Chaudry. She is a 70 year old woman. Family members have noted that she is more forgetful lately. She cannot remember conversations with people and forgets appointments with her doctor. She often misplaces important items like her keys and glasses. She is physically healthy but is concerned about her memory.

Prompts: *Would you get help for memory problems? What would make it more likely you would seek help?*

Intervention: *We know that people who get help for memory problems from their doctors earlier in the illness do better overall. They are able to plan for their future better and their families feel more supported.*
If you or someone close to you had memory problems, what kinds of information would make you more likely to get help for memory problems?

What form should the information take? E.g. paper, DVD, video in GP surgery

What would encourage you to read/see something about memory problems?

What age group would be best suited to receiving this information?

If you know of anyone else who may be interested in taking part, please let us know.

Would you be interested in giving us feedback about any leaflets or information videos we may produce in future?

Interviews continued until no new material was emerging, indicating theoretical saturation of data had been achieved.

5.4.3 Questionnaire development study

Another researcher (Julia Hailstone), who had contacted us to ask if she could be involved with our group for her DClinPsych project was simultaneously constructing and validating a questionnaire to assess attitudes to help-seeking for dementia in South Asian people. To do this, those who were willing and able to complete an additional questionnaire were asked questions from the Dementia Knowledge Questionnaire (Graham et al. 1997), their attitudes to help-seeking for dementia and whether they had personal experience of dementia. This initial questionnaire was modified after each focus group to refine the questions regarding attitudes to help-seeking as recommended by Ajzen in creating a Theory of Planned Behaviour questionnaire (Ajzen I. 2002) which was then used as an additional outcome measure in my Randomised Controlled Trial (see chapters 9 and 10). JH recruited participants from my focus groups initially but also added participants through snowballing and later completed administration of the questionnaire via online questionnaire.

5.5 Analysis

I audio-recorded focus groups and interviews and they were transcribed verbatim by an external transcription agency. I then removed identifying information to preserve anonymity. I took notes during the focus groups in

order to assist in identification of speakers when listening back to the recordings. I sent transcripts of individual interviews to participants for comments and alteration as a method of quality control and validation. I analysed transcripts independently from another researcher Amy Waugh (AW) to ensure reliability for emerging themes and concepts. Analysis of transcripts occurred concurrently with recruitment of new participants.

In order to analyse the transcripts, we initially familiarised ourselves with data, then generated initial codes, searched for themes among codes, reviewed the themes, defined and named them, and produced a final report (Braun V. and Clarke V. 2006). We used NVIVO software (Version 9.0) to assist in data coding, management and analysis. Themes were discussed at regular intervals by me and AW and the final coding scheme agreed by discussion.

Results for this study are presented in the next chapter.

6 : Qualitative study results

6.1 Participants and demographics

I conducted seven focus groups and five individual interviews, with 53 participants in total. The focus groups were held in West and North London, in: a Bengali community group; an Ismaili community centre; a Hindu cultural group and an Asian women's group. Participant demographic characteristics are shown in Table 6-1.

Characteristic	Number (percentage)/ Mean (range)	Characteristic	Number (percentage)
Mean age (range)	56.9 (18-83)	**Religion:**	
Female	34 (59)	Islam	39 (74)
Ethnicity:		Hinduism	11 (21)
Bangladeshi	32 (60)	Jain	1 (2)
Indian	17 (32)	Christian	1 (2)
Pakistani	2 (4)	No religion	1 (2)
Other	1 (2)	Unknown	0 (0)
Place of birth:		**Age at leaving full-time education:**	
Bangladesh	29 (55)	No formal education	7 (13)
Africa (various countries)	11 (21)	<10	2 (4)
India	9 (17)	10 to 18	24 (45)
Pakistan	1 (2)	19 to 25	11 (21)
UK	2 (4)	>25	7 (13)
Other	1 (2)	Unknown	2 (4)
Mean years in UK (range)	32.9 (4-53)	**Employment:**	
		Never worked	13 (25)
First language:		Retired	18 (34)
Bengali	30 (57)	Currently working	19 (36)
Gujarati	7 (13)	Full-time education	2 (4)
English	7 (13)	Unknown	1 (2)
Punjabi	3 (6)	**SOC group**	
Hindi/Urdu	4 (8)	Managers, directors and senior officials	3 (6)
Other	2 (4)	Professional occupations	8 (15)
		Associate professional and technical occupations	1 (2)
Marital status:		Administrative and secretarial occupations	6 (11)
Married/living with partner	35 (66)	Skilled trades occupations	7 (13)
Single	6 (11)	Caring, leisure and other service occupations	3 (6)
Widowed	5 (9)	Sales and customer service occupations	2 (4)
Divorced/separated	1 (2)	Process, plant and machine operatives	2 (4)
Unknown	6 (11)	Elementary/unskilled occupations	6 (11)

Table 6-1: Demographic characteristics of participants.

SOC = Standard Occupational Classification

6.1.1 Demographic characteristics

Participants were 58.5% female with a mean age of 57 (range 18 to 83 years). Most (74%) identified themselves as Muslim and 60% were of Bangladeshi origin. The majority of participants left school in their early teens and identified Bengali as their primary language. Most were married and had retired. There was a good range of countries of origin and occupations.

13/17 participants who filled in the more detailed questionnaire, knew someone with dementia, four of whom had cared for someone who had dementia.

6.2 Themes

I identified four main themes. These were: barriers to help-seeking for memory problems; the threshold for seeking help for memory problems; ways to overcome barriers to help-seeking; what features an educational resource should have. These are discussed below.

6.2.1 Barriers to help-seeking

I divided the barriers discussed into those that occur at the individual level, the societal/community level and the healthcare system level. These are shown in Box 6-1, along with how frequently they were mentioned.

Individual	**Frequency**	**Societal**	**Frequency**
Lack of acknowledgement there is a problem due to:		Perceived stigma of mental illness	10
Fear of institutionalisation	5	Stigma of cognitive symptoms	6
Lack of language to describe problems	4	Expectation that family should look after their own as long as possible	4
Denial from individual	3	Feeling dementia is a dangerous illness	2
Fear of the diagnosis itself	3		
Unwillingness to challenge family hierarchy	2		
Wish to maintain position in society	1	**Healthcare system**	**Frequency**
		Not knowing what help is available	10
Lack of communication	2	Feeling nothing can be done	4
Believing that memory problems are due to:		Language barrier	3
Old age	9	Lack of culturally appropriate help	2
Social isolation/stressors	9	Feeling the diagnosis itself can never be certain	1
Psychological cause/mental illness	6		
Another physical illness	2		
Spiritual cause	1	*Perception that GPs:*	
Feeling that responsibility for getting better lies with:		Do not have enough time in consultations	5
The individual themselves	2	Are not useful as a first point of contact	3
The family	1	Would not take concerns seriously	3
God	1	Would say memory problems due to old age	2

Box 6-1: Barriers to help-seeking for memory problems

6.2.1.1 Individual level barriers to help-seeking:

6.2.1.1.1 Memory problems are an inevitable and normal part of ageing

Some participants in each focus group commented that they frequently witnessed memory problems among older members of their families and communities or even in themselves. They regarded these as inevitable and normalised their occurrence, even where their descriptions suggested more serious problems.

> *"in reality, most of them are having the same problem. At least so many times in a day, my mum, that aunty, they forget things where they put it." Participant number 1, 67yo Bangladeshi Muslim woman, no education.*

> *"something is attributed just to old age and it's going to come and there's nothing you can do about it." P2, 52yo Indian Jain woman, tertiary education.*

6.2.1.1.2 Memory problems are not an illness

Another common belief was that social isolation or stressors could cause symptoms.

> *"The children have grown up, they have their own life, they are not living with parents, and they are feeling lonely, isolated. That's another problem for memory problems." P3, 68yo Bangladeshi Muslim woman, minimal education.*

The idea that memory problems may be due to spiritual wrongdoing was mentioned.

> *"it's just that you may not have done something in your previous life, you know, that you're getting some of these problems." P2.*

One participant expressed the view that it would be up to God to decide if the person has an illness for which help should be sought, although no explanation was given for how this would guide the decision-making process.

> *"Allah knows if it is an illness or not." P4, 66yo Bangladeshi Muslim female, no education.*

6.2.1.1.3 Individuals or families can make memory problems better

Other participants said that the person or their family could make themselves better.

> *"So he needs to share his pain or sorrow with a friend who can be assisting, can be supporting him or her. The more you share, you get more breathing space, so you can think better. The dementia we can cure or we build ourself…We need to come out of these things somehow." P5, 52yo Bangladeshi Muslim man, tertiary education.*

6.2.1.2 Societal level barriers to help-seeking:

6.2.1.2.1 Stigma of diagnosis

Another common theme was the stigma of mental illness and cognitive disorders, which is classed as a type of mental illness.

> *"there is a lot of stigma attached to psychiatric problems and memory falls within that domain." P6, 26yo Pakistani agnostic man, post-graduate student.*

Some participants in each group thought that the stigma of a memory disorder was much worse than that of a chronic medical disorder.

> *"most illnesses, …you can be distanced from them and you can deal with them on a practical level. You get diagnosed. You're treated, you do something to make it go away, or live with it, but there is a sense of separation, but with dementia it's more devastating, I think, because it completely takes over the person…it actually takes you away from who you are as a human being, with all these connections that we have." P7, 50yo Indian Muslim man, secondary education.*

Several participants agreed that the stigma in the UK would be less than in their home country.

> *"The stigma is less here than it would be back home. Back home our families would be sort of outcast, people would avoid going to their homes if they knew there was somebody suffering with this kind of problem." P8, 56yo Indian Muslim woman, secondary education.*

Participants also linked the stigma of dementia to ideas about dangerousness from neglect.

> *"people who are... have dementia not only mentally but sometimes become incontinent or they might be a danger to themselves or the society; they might walk away from the house or set the burner on or something." P9, 79yo Indian Hindu man, tertiary education.*

6.2.1.2.2 Good families look after people with dementia themselves

There was a perceived expectation in the community that families would provide care when relatives experience memory problems, without outside help. This was mentioned by a few participants and linked with respect for the affected person and the family hierarchy.

> *"it is in a way seen as a badge of pride if the family is looking after them whereas there is a lot of stigma in being transferred to mental health services or a care home where they could probably be better looked after." P6.*

> *"You couldn't quite discuss that he had memory problems with the wider family or whatever. It's just not done, that would be disrespectful so you know you cope." P2.*

One participant commented that families might only feel able to ask for help when the person with memory problems was near the end of their lives.

"You deal with it as best as you can. Maybe they start thinking about receiving help in terms of terminal care." P10, 26yo Indian Hindu woman, post-graduate student.

Some expressed the view that there was more support available in their home country but this was not accepted by all participants.

"Back home we've got a lot of support in these sort of things. But here, you are stuck in the world by yourself." P5.

"I don't think so, it's same as here…There are worries everywhere, any country, I believe." P11, 64yo Fijian Muslim woman, secondary education.

6.2.1.3 Healthcare system level barriers to help-seeking:

6.2.1.3.1 Lack of knowledge of help available

A commonly mentioned barrier was being unaware of what services were available for cognitive problems.

"people don't know about the services ….there's lack of knowledge about the services."P6.

Many participants said they would see their GP in the first instance about memory problems and expressed the view that health and social care support was very good in the UK. Others had reservations, saying that GP time was limited and GPs would prioritise severe dementia and physical illnesses and dismiss memory problems as being due to old age. Some participants also felt

that services needed to have a better understanding of cultural needs and the lack of it led to worse outcomes.

> *"there are some multifactorial issues as to why Asians don't seek (help) and when they do seek then there isn't a lot of information provided to them so it prevents them from seeking help in the first place and if they do end up in care homes…they aren't looked after as well as they could be." P6.*

Some participants questioned the validity of a diagnosis.

> *"dementia, how certain are you, from after your diagnosis, that it is dementia, and it's not just general forgetfulness?" P12, 44yo Indian Muslim woman, secondary education.*

One participant commented that memory and cognitive problems were not discussed at GP appointments until there was a crisis:

> *"when they go to see the GP, the conversation of tell me what's happening to you, they come out with physical symptoms rather than you know impairment of other kinds…It doesn't come up until you're into crisis." P2.*

Some participants also mentioned that services may be harmful, feeling afraid that disclosing cognitive symptoms could result in having to leave their own home.

> *"I think some people don't want to tell other people that they're forgetting, they're scared that they would think that they're*

crazy or if they're living alone, try and get them admitted or something. People are scared of that, you know." P8.

6.2.2 High threshold for help-seeking

Several participants in each group felt that help should be sought for memory problems as soon as possible. Many complained of memory problems, but only one had sought help.

Some participants said that if symptoms were more frequent or were troubling the individual then they should get help but this was difficult to quantify.

> *"I think if it's happening more often then it's a cause for concern." P13, 68yo Indian Muslim woman, secondary education.*

More commonly, people said they would get help if there was a specific event that was unusual or worrying.

> *"If I forget an appointment, or if I forget the timing of an appointment, I'd consider that a minor matter and it wouldn't alarm me. But if I got up and I didn't know what day it was, or what the date was, or if I found myself and didn't know where I was or how I'd got there, then I think it would be a cause for me to be alarmed." P14, 49yo Pakistani Muslim woman, secondary education.*

Participants also said they would get help for behavioural changes, self-neglect, psychological symptoms like anxiety and any sort of risk, such as fire risk or not remembering if you had taken your medications. However, even the risk of fire was felt not to be significant unless it happened repeatedly.

> *"There would be stronger signs if it's constant. If it's a one-off example you can bypass that. If it's constant, silly things like leaving the gas on, leaving the fire on and then it's getting more and more severe, then leaving the gas on is a very good danger sign for a family…when families need to be alerted, and say "ok, we've got a problem." P15, 36yo Bangladeshi Muslim male, tertiary education.*

> *"we have people that when they can't take care of themselves but if they have the capacity for the basics like helping with cooking or going for their walks or just taking care of their hygiene and if that is compromised then that is when we seek care but until then it didn't seem like it was necessary as it wasn't that severe." P10.*

6.2.3 Ways to overcome barriers to help-seeking

I asked participants what would encourage them to seek help earlier for cognitive problems.

6.2.3.1 Normalising help seeking and breaking down stigma

Several suggested that normalising help-seeking and breaking down the stigma associated with both the symptoms and help-seeking might encourage earlier help-seeking.

"The only thing one can do is to tell the particular person that this is nothing uncommon and nothing to be embarrassed about. It happens to all of us and encourage her to seek medical help." P9.

6.2.3.2 Emphasis that dementia is a physical illness

Some participants mentioned other illness awareness campaigns that they felt had made a significant impact and this highlighted the importance of emphasising the physical rather than mental nature of illness.

"if people were introduced to the fact that there is a physical cause…I think if things are explained in a simple and logical manner it'll become more approachable, and understandable, and acceptable." P14.

6.2.4 Desirable features of an intervention

6.2.4.1 Trusted source

Several participants stated that the information should come from a trusted source. Letters from the NHS and particularly from GPs were felt to have considerable impact and were likely to be read.

"You see, because I find if any medical letter comes in, NHS, recently I got a couple of them so I'll read through it whether it concerns me or not, I think one should know." P16, 73yo Indian Hindu man, tertiary education.

6.2.4.2 Target audience

Some participants felt information should be targeted at South Asian people of all ages, others suggested targeting older people, or those aged 30-40 or specifically women because they would be caring for older relatives. Most agreed literature should feature South Asian people:

> *"something you can identify with, because usually you know whatever you see, you see a grey haired person and usually a white person so you think well there isn't a connection." P2.*

6.2.4.3 Presentation

Participants suggested that information could be presented in leaflets, a DVD, TV adverts, and videos on GP practice waiting room screens or a combination of these. DVD was the format most frequently endorsed as this would provide more detailed information, ideally presented as a personal story.

> *"I think the fact that you actually had a description of a person going through the problem caught my interest…That's how I relate to things." P14.*

Participants felt it was important to include information about symptom progression and when to seek help as many people might equate the term dementia with very severe dementia.

"understanding that you can carry on you know and just understanding the progression because usually people associate dementia with those last stage, you can't recognise anybody, you're incontinent - they only recognise that very end stage they don't recognise from the initial from the very start, that is not people's conception." P2

They felt the benefits of help-seeking should be emphasised.

"While there isn't a cure, I think it's important to realise that there is a lot which can be done for the person during the process." P14.

6.3 Differences in themes by demographic factors

I was interested to explore whether any of the themes that emerged during the groups differed depending on participant characteristics. Using NVIVO software I searched through codes and themes to see if any patterns emerged. I looked for differences by gender, religion, country of origin and length of time in the country but did not find any differences in concepts expressed according to these factors.

6.4 Discussion

This qualitative study was the largest to date of the UK South Asian community's beliefs about memory problems and considerations about barriers which can delay help-seeking for these symptoms and the first to consider what intervention might make a difference. Previous studies have

shown that beliefs that dementia is part of normal ageing, and a reluctance to seek help for memory problems, are common even amongst the majority population but these beliefs are more common in minority ethnic groups and there are more concerns about stigma (Bunn et al. 2012). This study confirms these findings but also provides more detail on reasons underpinning delays in help-seeking and ways to overcome barriers to help-seeking.

I found as others did that there was stigma but more details of what it was about. Stigma was linked with ideas of “madness”, lack of physical aetiology and lack of treatment. Using a case discussion also helped to highlight the dilemma that people with cognitive problems are likely to face – namely, that forgetfulness is a common and normal experience so it is difficult to differentiate it from significant cognitive impairment but the study adds to the literature by finding a particularly high threshold for identifying abnormality in this group. I recruited a wider range of participants than previous studies including those with direct experience of caring for someone with dementia and sought potential solutions to the barriers found.

Overall participants recognised memory problems and felt concerned about them but there were many barriers to help-seeking, particularly the belief that memory decline was inevitable and not an illness. Reasons behind denial of symptoms, such as wanting to maintain ones’ position in society or in the family hierarchy and the fear of institutionalisation and the stigma it carries were interesting and useful. Thus an intervention could tackle stigma around

dementia by re-framing it as a possible sign of an underlying physical illness. The study suggests that an intervention should give information about key symptoms which would lead to help seeking and how that could be beneficial to the person with dementia, as well as the family. Thus getting help is not seen as relinquishing ones' responsibilities, but rather living up to them so that the person with dementia can live as fulfilling a life as possible. Equally, help-seeking could be useful in allaying fears of those who are not developing dementia.

In this participant group, visual presentation of information was felt to be desirable and people felt more able to relate to a person's story rather than purely clinical information. The source of the information should be trustworthy and the NHS fell into this category.

6.5 Reflexivity

Reflexivity is the process of reflecting systematically on the process of knowledge construction, particularly with regards to the researcher themselves and how they might influence the research. This is particularly relevant in qualitative research, which often involves more contact between the researcher and participants and often in a less structured way. I was aware while conducting this research that my clinical and academic background would have an influence on the research questions I chose to investigate, how I conducted the research, what findings would be most salient to me and how I framed the conclusions, as is widely recognised in qualitative research

(Malterud 2001). I was conscious that, as a doctor specialised in diagnosing and treating dementia, I have a medical understanding of memory symptoms and advocate early presentation to medical services. During facilitation of focus groups and while conducting interviews, I made every effort to be open to what participants wanted to talk about. Having co-facilitators helped to ensure a wider range of experiences was explored. I also had a psychology graduate reading and coding the interviews independently of me to increase the chances of being receptive to themes that were emerging from the data rather than creating themes from my own perspective.

I am South Asian myself and was also aware that my own experiences of my culture should not influence my facilitation of focus groups or interpretation of interviews and again, having co-facilitators and another person to interpret the data was helpful to provide alternative perspectives.

6.6 Conclusions

I have further explored barriers to help-seeking for dementia in the South Asian community in this study and highlighted ways to overcome these barriers. My findings suggested that an intervention should be targeted at known barriers to help-seeking within this community, should use personal narratives and should come from a reliable and trusted source. In the next chapter I examine the literature regarding what works to alter behaviour and how I integrated this

information along with findings from my systematic review, qualitative study and published guidance to design my intervention.

7 : What works to change health-related behaviour?

In previous chapters I have described work to find what interventions work to increase dementia diagnoses in the general population, and findings from my qualitative work as to what may overcome barriers to help-seeking for dementia in the South Asian population. In this chapter I examine what works to change health-related behaviour in general and what factors affect behaviour related to mental health concerns and dementia in order to further inform the design of my intervention.

7.1 Changing peoples' health-related behaviour

The UK government spends millions in information campaigns in other healthcare areas such as encouraging healthier lifestyle or reducing smoking. A review of these campaigns suggests that information about health topics can be part of a tool for changing behaviour but simple provision of information alone is not sufficient (Robertson R. 2008). This report reviewed interventions aimed at encouraging healthier behaviours, specifically with regards to healthy eating, physical activity, smoking and alcohol misuse. It outlined findings about how, what and to whom we should seek to provide information to change health-related behaviour and I list the salient points below:

- The content and source of the message, the way it is delivered and the target population may all affect its impact.

- Simple messages may be easier to communicate but there is no evidence that these are more effective than more complex messages.
- Some research suggests that people view the government with mistrust, so that health messages are perceived in a more positive light if they come from an independent source such as community organisations or religious organisations depending on whom those targeted by the information view as more trustworthy or relevant to their lives.
- Health messages regarding lower risk behaviours benefit from framing in a positive light and highlighting the benefits of engaging in certain behaviours, whereas higher risk behaviours seem more amenable to change if the dangers of the behaviour are highlighted.
- The impact of health messages are further affected by the mind-set and 'stage of change' that the recipient audience is in. People who are already worried about their health will respond more to a health promotion message than those who are not.

These are relevant considerations for my own intervention, which is encouraging healthy behaviour, namely getting help for cognitive symptoms as early as possible.

Another paper highlighted that how a message is delivered is also important (Noar et al. 2007). Information campaigns can be generalised or *untargeted*, meaning they are sent to the general public without any form of targeting. In contrast, *targeted* interventions are designed to be relevant to a particular

group of people who share common characteristics, such as ethnic group or religious affiliation reference. Finally, *tailored* interventions are even more specific and designed to be relevant to a particular individual. By taking that individual's personal concerns into account, the intervention is made even more salient. Targeted or tailored interventions are generally more effective than untargeted ones and have the potential to effect behavioural change (Kreuter and Skinner 2000).

7.1.1 Relevant principles for design of my intervention

Based on these principles, encouraging people from a particular ethnic group to access timely help for dementia should ideally involve at least a targeted intervention that specifically addresses barriers to help-seeking within that group. It should come from a trusted source and be framed in a positive way, emphasising benefits of help-seeking rather than negative consequences of not seeking help. This supports views from participants in my qualitative study (Chapter 5) who said an intervention should contain information about the benefits of help-seeking and should be sent from a trusted source such as the National Health Service.

In order to further inform development of my intervention, I explored what health-related behaviour change interventions in the field of mental health or dementia, had been previously designed and executed and what elements are important to include in behaviour change interventions.

7.2 Changing behaviour relating to mental health concerns

One study found that a video intervention about mental health services increased positive attitudes towards help-seeking for mental health problems but this did not necessarily translate into positive intentions to seek help for interpersonal difficulties (Demyan and Anderson 2012). Another study found that people who received a pamphlet about depression and its treatment expressed a greater intention to seek help for depression and suicidality and felt that antidepressants could be helpful (Bhugra and Hicks 2004). Actual help-seeking was not measured and the authors note that only 40% of those approached for participation agreed to take part. This raises the question of how to reach people who are not interested in receiving health related messages.

A systematic review of eight different interventions designed to increase knowledge about mental health problems and encourage help-seeking, found that information about mental health improved attitudes to help-seeking but did not alter help-seeking behaviour (Gulliver et al. 2012a). An exploratory RCT by the same group found that an internet intervention providing information about mental health problems increased positive attitudes towards help-seeking and reduced stigma but did not increase help-seeking (Gulliver et al. 2012b). However, this study was underpowered to detect an effect. Overall, this body of research suggests that providing information about an illness may improve attitudes towards help-seeking for that behaviour but it does not alter

stigma around the condition and it is uncertain whether it translates to actual help-seeking behaviour. All of these interventions provided generic information about mental health so were not targeted in any way. Their negative findings could be due to this lack of targeting.

7.2.1 Relevant principles for design of my intervention

Overall this literature highlighted the importance of designing an intervention to be targeted to a particular audience and putting information in a positive light. Findings from my qualitative study are therefore crucial, as an intervention targeting a specific ethnic group is more likely to be effective compared to one aimed at the general population that does not tackle specific barriers to help-seeking.

7.3 Changing behaviour relating to cognitive complaints

One study compared participants who sought help for subjective memory complaints versus those who did not seek help. The objective cognitive impairment in both groups was the same but those who sought help were more likely to believe their symptoms had more serious consequences and were also more likely to believe the symptoms to be due to a biological cause that may be amenable to medical treatment (Hurt et al. 2012). However, this was a retrospective analysis and there is not enough information to be confident what factors would alter help-seeking behaviour for cognitive complaints. In line with previous evidence, it does suggest that altering beliefs about

dementia so that it is clear it is a biological illness with potentially serious consequences, will encourage help-seeking behaviour for it.

7.3.1 Relevant principles for design of my intervention

Participants in my focus groups also emphasised the importance of highlighting the biological nature of dementia. This was related to decreasing stigma but also could emphasise the seriousness of the illness and that something can be done about it. This overlaps with the study described above.

With these principles and findings from my systematic review and qualitative study in mind, I read the literature about designing interventions to change behaviour.

8 : Designing interventions to change behaviour

In this chapter I define behaviour change interventions and describe theories that are used to explain behaviour. I also describe how I selected and used a theory about behaviour change and behaviour change framework to design my intervention.

8.1 Complex interventions

A complex intervention is defined as one that has a number of components. Complexity may be due to the number of components in the intervention, the complexity or number of behaviours that it targets, the setting in which the intervention is delivered, the range of possible outcomes or any combination of these factors.

My planned intervention was to change attitudes to help-seeking for dementia and it would be likely to be defined as a complex intervention. The Medical Research Council guidelines on designing complex interventions (Craig et al. 2008) recommends four main stages in intervention design:

1. A development phase to identify pre-existing evidence, develop theories and model processes and outcomes.
2. Feasibility or piloting to estimate sample sizes, evaluate processes and ability to recruit.
3. Evaluation to assess effectiveness, cost-effectiveness and understand the process of change.

4. Implementation for longer-term follow-up and wider disseminations.

They suggest that these processes are inter-linked and need not occur sequentially but will more likely occur in tandem, iteratively and with feedback from one stage informing another.

Complex interventions should be based on theoretical models so that the active components of the intervention and mediators of the effects can be analysed, for example, whether knowledge change or attitude change makes a difference to behaviour (Craig et al. 2008). These guidelines provide a good base for designing complex interventions, although some have argued that they need to be updated to include new methodologies for implementation (Moniz-Cook et al. 2011).

8.2 Behaviour change interventions

The NICE guidelines on behaviour change interventions also recommend examining the context of the desired behaviour, the theory behind behaviour change, the desired outcome and suggest that any description of such an intervention should include explicit instructions about how the intervention was designed and delivered in order to allow replication by others (The National Institute for Health and Care Excellence 2007).

Behavioural change interventions are important in addressing population health matters but they are difficult to design (Michie 2008). This is because

such interventions often comprise several interacting components or heterogeneous behaviour change techniques. It can be difficult to standardise content and delivery, as the local contexts in which the interventions are delivered vary. Additionally there are organisational and logistical difficulties in applying experimental methods to service or policy change probably related to the length and complexity of the causal chains linking intervention with outcome (Abraham and Michie 2008).

The rationale for basing intervention design on theoretical models is not based on effectiveness, as the evidence for the associations between theory use and effectiveness is mixed. However, this may be due to the lack of a systematic approach to using theory to guide intervention development (Michie et al. 2014). Basing intervention design on a theoretical model is useful as describing an intervention and all behaviour change techniques used clearly will enable other researchers to replicate the intervention and can also ensure that we can understand which specific behaviour change techniques are effective and which are not (National Institute for Health and Clinical Excellence 2007).

8.2.1 The process of designing an intervention

The first stage of designing an intervention to change behaviour involves identifying and understanding the theoretical determinants of the behaviour in question. A behaviour change theory can be selected which is appropriate for the behaviour being studied. Then behaviour change functions, or

mechanisms of influencing behaviour, need to be employed in designing the intervention in order to bring about the desired change.

So far, in the process of designing my intervention, I had:

1. Identified that this would be defined as a complex intervention and one aimed at changing behaviour.
2. Conducted a literature search to identify pre-existing evidence about successful interventions.
3. Conducted qualitative work to further understand the processes and important outcomes involved in the relevant behaviour.

The next stage was to identify an appropriate theory of behaviour change as recommended by published guidance, in order to better understand the processes of change involved and better enable replication in the future.

8.3 Behaviour change theories

Many theories have been applied to health behaviours and provide targets for changing it but no single theory accounts for all the variation in human behaviour. There are over 83 different behaviour change theories, many of which have significant overlap with each other (Michie et al. 2014). Automatic processing theories are focused on mechanisms underlying behaviour that does not involve reflective or conscious choice, whereas reflective choice theories focus on processes underlying conscious action and some theories

have integrated these two separate ways of thinking about behaviour (Strack and Deutsch 2004).

I set out to select a theoretical model on which to base my planned behaviour change intervention which was relevant to the type of behaviour being studied and the factors which are important in initiating that behaviour.

8.3.1 The Theory of Planned Behaviour

Deciding whether or not to seek help for dementia is unlikely to be an impulsive choice and is more likely to involve conscious reflection and weighing up of pros and cons. This has been shown in my systematic review and qualitative study which found that the factors involved in minority ethnic groups making this decision include beliefs about the illness, concern about what others in their social group would think and the ability to seek help based on the local healthcare professionals and systems involved (Mukadam et al. 2011a;Mukadam et al. 2011b). The Theory of Planned Behaviour (TPB)(Ajzen I. 1985) explains this type of health behaviour. It incorporates the following three determinants of behaviour:

1. Behavioural Attitudes, which is the degree to which a behaviour is evaluated by the individual as being favourable or unfavourable for the person to complete. This is influenced by Behavioural Beliefs relating to the advantages or disadvantages of performing a behaviour.

2. Subjective Norms or the perceived social pressure to perform or not perform a behaviour. This is affected by Normative Beliefs regarding individuals or groups of people who would approve or disapprove of the behaviour in question.
3. Perceived behavioural control, which is the individual's perceived ability to effectively complete that behaviour. This is influenced by Control Beliefs which affect a person's perception about how easy it is to complete a behaviour.

These three factors together shape an individual's behavioural intentions and subsequent behaviour, as shown in Figure 8-1 below.

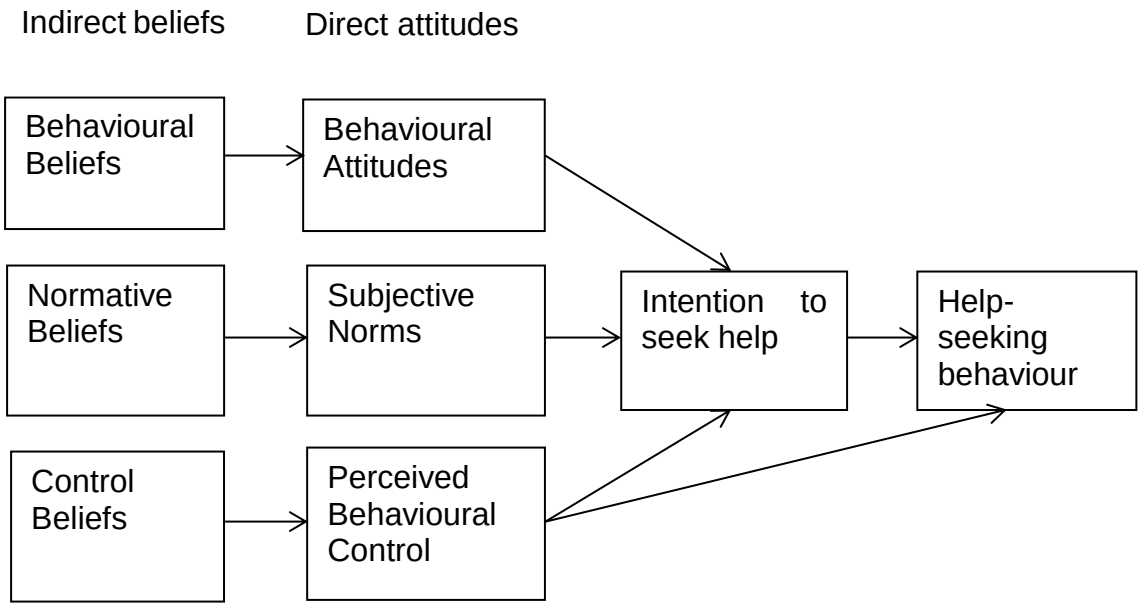

Figure 8-1: The theory of planned behaviour model (Ajzen, 1991) as applied to help-seeking for dementia

The Theory of Planned Behaviour has been widely used in examining health-related behaviours and in a meta-analysis has been found to explain over 40% of the variance in intention to carry out a behaviour (Godin and Kok 1996). More recently, it has been criticised for being too simplistic, not explaining enough variance in behavioural intention and for interventions which have used it not being effective (Sniehotta et al. 2014). However, it is a theory that is not as simplistic as it may seem initially and does expect feedback to be occurring through the model. It also consistently explains a large percentage of variation in intention to carry out a behaviour and has also been shown to predict actual behaviour in many health-related behaviours (Ajzen 1991;Ajzen 2015).

Moreover, the theory incorporates three factors which I also found to be important in my qualitative work, namely, attitudes towards help-seeking, which are based on knowledge; concerns about social approval and beliefs about the ease of seeking help. This made it a good fit for basing my intervention design on.

8.3.2 The Behaviour Change Wheel

Another approach to designing a behaviour change intervention is the Behaviour Change Wheel (Michie et al. 2011). This approach was generated based on a systematic review of behaviour change interventions followed by synthesis of 19 behaviour change frameworks in the literature, development of the new model and a test of its reliability. It is intended to provide

comprehensive coverage of all behavioural interventions which link to an overarching model of behaviour and has internal coherence. This model was helpful in thinking about designing my intervention as it specifies behaviour change functions for incorporation into interventions as well as explaining determinants of behaviour.

8.3.2.1 The COM-B model

The COM-B model is at the heart of the Behaviour Change Wheel and it identifies sources of behaviour that could be fruitful targets for an intervention. It is named the COM-B model as behaviour (B) is determined by: capability (C) - the individual's ability to engage in the behaviour; opportunity (O) - factors outside the individual that make the behaviour possible and motivation (M) - all internal processes that produce and direct behaviour.

The outer layer of the Behaviour Change Wheel surrounding the COM-B model is a list of nine intervention functions which are selected depending on what factors are relevant to producing that behaviour, for example, if practical capability is a key factor in limiting performance of a task, the intervention would seek to remove any restrictions, perhaps through environmental restructuring.

Here I consider what elements of the COM-B model underlie help-seeking for dementia and later I outline what intervention functions from the Behaviour Change Wheel I included in my intervention.

1. **Capability.** Knowledge about dementia and help-seeking is relevant to psychological capability, as are physical and cognitive skills required to seek help.
2. **Opportunity.** The environmental context and resources and social influences are relevant to this.
3. **Motivation.** Social role or identity would be relevant, as would optimism, belief about consequences of help-seeking and beliefs about one's capabilities

8.4 Linking my findings with behaviour change theory

I found the main barriers relevant to help-seeking for dementia in this group of participants, through literature review and conducting focus groups, as described in previous chapters. In Figure 8-2 I show how these findings link with the Theory of Planned Behaviour (TPB) and the COM-B model.

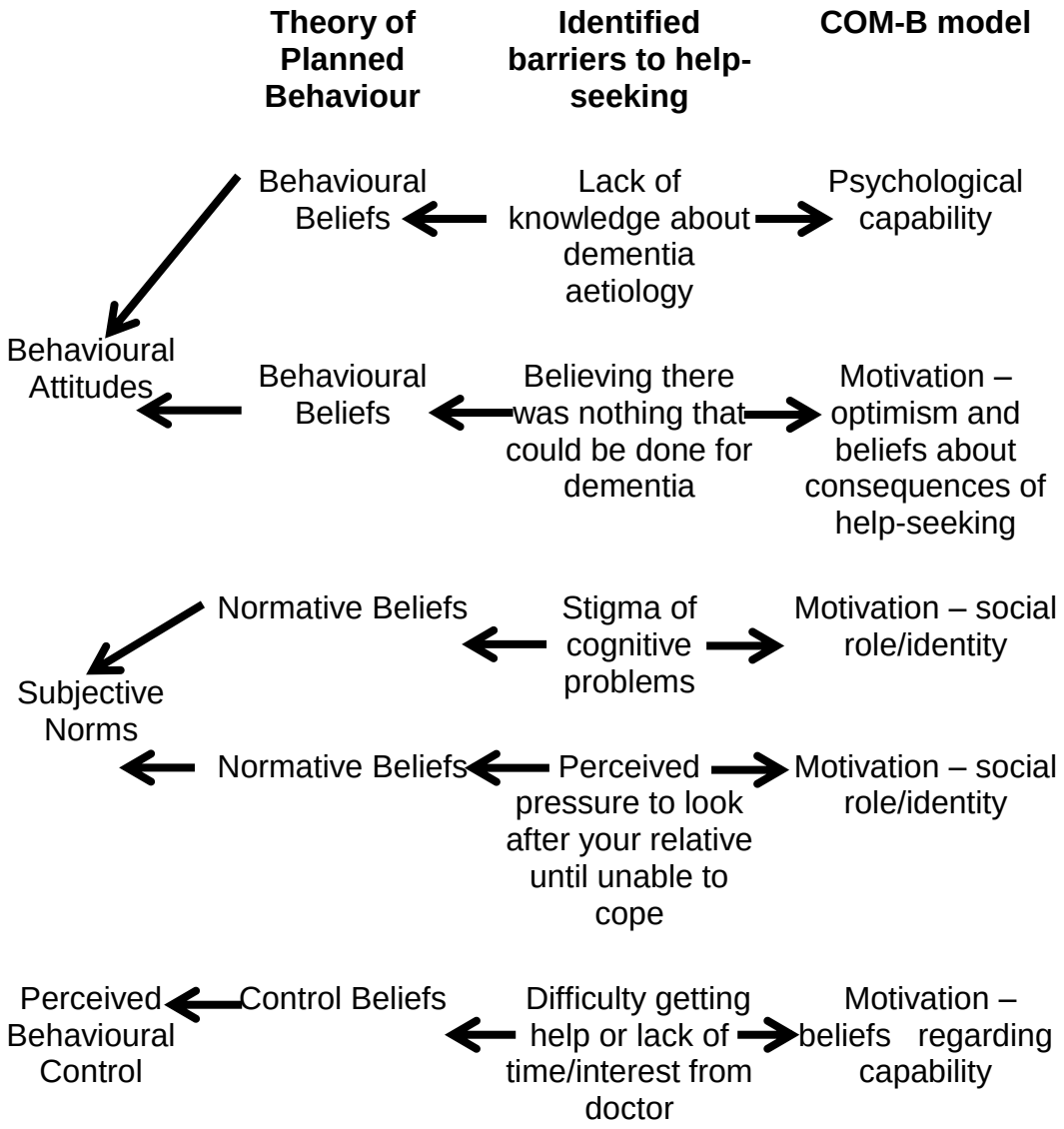

Figure 8-2: Mapping barriers to help-seeking onto behaviour change theories

As the figure shows, barriers to help-seeking for dementia were relevant for all domains in the Theory of Planned Behaviour and were mostly relevant to Motivation and Capability in the COM-B model.

I now had information about barriers to help-seeking for dementia in the South Asian community as well as how these mapped onto determinants of behaviour change theory. I then had to decide on the scope of my intervention, what intervention functions I would incorporate into it and its final design.

8.5 Scope of the intervention

Using the principles of intervention design, these barriers to help-seeking for dementia can be targeted in a systematic way. Tackling all of the individual, societal and healthcare-related barriers would involve a multi-faceted intervention focused on individuals, society in general (to address stigma) and healthcare professionals as well as perhaps addressing healthcare organisations. This kind of intervention would be extremely complex and potentially very expensive. It would also be difficult to assess which elements were effective if so many were applied at once.

Most of the knowledge about barriers to help-seeking for dementia is about individual factors. These seem to be a relatively realistic target for intervention with potentially lower cost than targeting larger areas of society or the healthcare system. It is important that interventions are economically possible and scaleable if they are going to be used in the future. I therefore chose to focus the intervention on individual barriers to early help-seeking for dementia with some focus on the perceived societal pressures and stigma around the condition, as well as providing information about the help that is available.

8.6 Format of the intervention

Focus group participants also discussed how they would like an intervention to be delivered and I used this in my design:

- Participants wished the material to be presented as a story or personal narrative that people could relate to.
- The intervention should come from a trusted source such as a community centre or their doctor.
- The materials should be visual (as opposed to just verbal) and in multiple formats.
- They said it was important to keep the language simple and ideally present the intervention in Bengali as many in the community were felt to have relatively low literacy levels.
- There were different points of view about which age group to target with the intervention. Some participants stated that only those who have memory problems should be sent information about it. However, a significant number of people felt that all age groups should be informed about dementia and the majority of people said that those over the age of 30 should be targeted.

8.7 Intervention design – behaviour change techniques

There is an association between the number of theoretically-based intervention components and successful behaviour change (Michie 2008) so a

behavioural change intervention should try to encompass as many intervention components or functions as possible. The Behaviour Change Wheel (Michie et al. 2011) described above lists nine different intervention functions which are: education, persuasion, incentivisation, coercion, training, restriction, environmental restructuring, modelling and enablement. Of these, I selected the following six which have relevance to encouraging earlier help-seeking for dementia (the definitions are as described in Michie et al 2011):

1. Education – Increasing knowledge or understanding. The intervention should focus on educating people about the aetiology of dementia. It would be important to emphasise it is a physical illness, like diabetes for example, describe its symptoms and the usefulness of help. This technique can also be used to inform people about the healthcare system, how to get help and why.
2. Persuasion – Using communication to induce positive or negative feelings or stimulate action. Positive imagery can be used to create better associations with help-seeking and prompts can be used within the intervention to stimulate action.
3. Incentivisation – Creating expectation of reward. The intervention can emphasise that help-seeking can lead to diagnosis and treatment or knowing that you do not have dementia.

4. Coercion – Creating expectation of punishment or cost. The possible risks of not getting help early for dementia can be shown, such as uncertainty about not knowing what is wrong.
5. Modelling – Providing an example for people to aspire to or imitate. Using a case example to illustrate the benefits of seeking help could be helpful and it would also help to address the concerns people may have about stigma or being judged negatively for seeking help. Help-seeking could be re-framed as a way of fulfilling your responsibilities towards your relative by ensuring they get the best possible care, rather than as a relinquishing of responsibility.
6. Enablement – Increasing means/reducing barriers to increase capability or opportunity. This would be a step beyond just education and may involve addressing psychological capability and providing strategies to increase the opportunity to seek help, for example by highlighting that your GP can arrange for referral to a memory service.

These functions have considerable overlap with features mentioned by focus group participants as being important barriers to help-seeking and as being desirable in an intervention. Particularly striking was the frequent mention by participants of incorporating a case story into an intervention. This could provide education, as well as modelling, incentivisation, coercion and persuasion.

8.8 Incorporating my qualitative findings, behaviour change theories and behaviour change design

Having selected the theory on which to base my intervention, the intervention functions I should include, the scope of the intervention and its format, I had to synthesise these factors together to produce an intervention.

My results indicated the intervention should be primarily visual in presentation, written and in video form, targeted at those at least over the age of 30 and should come from a trusted source. It should aim to address barriers to help-seeking through the use of case examples, in order to educate people about dementia, emphasise the benefits of early help-seeking and reduce the stigma related to early help-seeking.

I used these principles to write a script for a video about dementia and a leaflet. The video involves a woman describing her mothers' experiences of memory problems and her hesitation in seeking help, then goes on to describe the outcome of their help-seeking, the diagnostic process, what dementia means and how seeking help was beneficial for her mother and the whole family. The leaflet describes a case vignette similar to the one used in focus groups, about a woman with memory problems. It then goes on to describe what dementia is, why seeking help for it can be beneficial and how to go about seeking help. The script and leaflet text were shown to colleagues working within clinical and research settings, as well as people working in communications industry,

independent from the research setting. The interventions were modified according to feedback and the final versions were then translated.

8.8.1 Translation and back-translation

The leaflet text and video script were translated into Bengali by a native Bengali-speaker who was also a medical professional. Once translated, the Bengali was back-translated into English by a medical professional who was fluent in Bengali. I compared the original and back-translated versions of the texts and resolved any discrepancies through discussion with the translators.

8.8.2 Layout and design

University College London media services provided the design and layout for the leaflet. They were given the English and Bengali text and I discussed with them the incorporation of images. UCL media services also filmed, produced and edited the video using two volunteers who acted as the mother and the daughter in the video. Stills from the video were incorporated into the leaflet, to provide continuity across the intervention. The video was transferred to a Digital Versatile Disc (DVD) and the start menu on this linked to either an English version or Bengali version of the video. The leaflet was printed double-sided with the English text on one side and the Bengali text on the other.

8.9 Feedback on the intervention

8.9.1 Professionals

I showed the leaflet and DVD to other researchers within the UCL Old Age Psychiatry department, Old Age Psychiatry clinicians, a patient representative member of my steering group committee and Bengali friends and colleagues. I used their feedback to make minor changes to the leaflet and DVD. Most people approved of the case study style description, the use of simple language to explain the illness and emphasis on the physical nature of dementia. The main changes suggested were to:

- Remove the logo for UCL division of psychiatry as the study was not funded by UCL and as it may be stigmatising for some people
- Consider including the patient's perspective on the DVD
- Substitute pictures of male White doctors in a white coat for an alternative that is less paternalistic and ethnically appropriate
- Consider adding in a Sylheti version of the video as most Bengalis in London speak this rather than formal Bengali.

8.9.2 Focus groups in a community centre

I then conducted two focus groups in a Bengali community centre which had been involved in my previous qualitative work. Participants seemed to like the leaflet and appreciated the message that dementia is a physical illness. They felt the DVD may not be watched but that the intervention was generally more

likely to be looked at if there was an NHS logo on the front, especially on the envelope. Participants also felt that it would be better to send the intervention to those over the age of 50 as the information would be more relevant than to a younger age group and people of this age may be making decisions about healthcare for older family members. There was some debate over which word to use for dementia as there is no equivalent term in Bengali so it was decided that the English word for it would be best. Participants said it would be good to hear from the patient herself in the film and that there should be a Sylheti version of the film. Sylheti is a dialect of Bengali that is widely spoken by the Bangladeshi community in London and participants felt that as many people in their community had little education, a Sylheti video would be more accessible than a Bengali one or Bengali and English text.

8.10 Modifications to the intervention

Based on feedback from professionals and South Asian community members, I did the following:

1. Added the NHS logo onto the leaflet
2. Filmed another section of the DVD in which the patient with dementia talks about her experience of getting a diagnosis and how this has been a positive experience
3. Arranged for the whole DVD to be dubbed in Sylheti and for a Sylheti version to be one of the options on the DVD start menu.

4. For the Randomised Controlled Trial part of my study, I also decided to target people over the age of 50 instead of over the age of 30 as originally planned.

The final English and Bengali versions of the leaflet and video script can be found in Appendices 6, 7 and 8 respectively.

9 : Pilot cluster randomised controlled trial - Methods

9.1 What is a pilot randomised controlled trial?

It is common to carry out smaller scale trials before a full-scale RCT to check the procedures involved and the acceptability of the intervention being trialled. These smaller scale studies are called ‘pilot’ or ‘feasibility’ studies, often interchangeably. The National Institute of Health Research defines a feasibility study as one that is designed to test whether the study can be done, i.e. whether it is possible to recruit and administer processes as intended in a full trial. A pilot study is defined as a smaller scale version of the main trial (National Institute for Health Research 2015). To clarify this definition further, various authors have conducted reviews of the literature, combined with canvassing opinion from funders (Whitehead et al. 2014) and journal editors (Arain et al. 2010) and a Delphi consensus study (Eldridge et al. 2016). All of these papers have concluded that feasibility studies are an overarching term for preliminary studies and pilot studies are a subset of feasibility studies that resemble the intended trial in aspects such as having a control group, randomisation (Whitehead et al. 2014), sample size calculation and plans for a further study (Arain et al. 2010).

The main functions of a feasibility study are to check: recruitment capability and resulting sample characteristics; data collection procedures and outcome measures; the ability to manage and implement the study and intervention and

test the preliminary evaluation of participants' responses to the intervention (Orsmond and Cohn 2015).

In this chapter I describe how I tested the acceptability of the intervention I developed and the feasibility of recruiting and following up participants. As I was testing whether it was possible to conduct the trial and also calculated the sample size, carried out randomisation and had a control group, it would be classified as a pilot study.

9.2 Research Governance

I obtained research ethics approval for this study at the same time as the focus groups and all documentation for this can be found in Appendix 12.

I formed a project steering committee consisting of my two supervisors, other researchers who were involved with the initial qualitative work, a qualitative researcher, the director of a community organisation, a carer and myself. Initially the steering committee met every three months to review progress and plan the study. However, for the RCT, I met only with my supervisors at regular intervals as the project and intervention had been designed.

9.3 Aims

1. Test the feasibility of conducting a cluster randomised controlled trial of this intervention.
2. To test acceptability of the newly developed intervention.

9.4 Hypotheses

I hypothesised that at least 70% of participants who expressed an interest in participating would enrol and that 70% would find the intervention acceptable. I also hypothesised that I would be able to follow up 80% of participants who enrolled initially.

My secondary hypothesis was that the intervention might have an impact on participants' attitudes to help-seeking for memory problems and their knowledge about dementia.

9.5 The intervention

As described in the previous chapter, the intervention consisted of a DVD that could be played in English, Bengali or Sylheti, sent out in a clear envelope with an English and a Bengali leaflet. A sample intervention pack is included with this thesis (see insert at the end of this thesis). The intervention was sent out to participants who agreed to be in the study, with a letter on headed paper from their GP practice. I agreed the text of this letter with the GPs. The letter stated that the GP practice was working to highlight the importance of certain health topics within the South Asian community and advised participants to look at the enclosed information. It emphasised that the information was not being sent because the GP had any concerns about the person's memory but was being sent to everyone. A copy of this letter is in Appendix 9.

9.6 Sampling frame and participants

I recruited primary care practices that had South Asian patients. Initially I contacted GP surgeries in Camden and Islington that I knew of through my clinical and research work. As the study was funded by a fellowship from the National Institute for Health Research, it was adopted onto the Clinical Research Network (CRN) portfolio. The CRN is an organisation with branches across England. Its aim is to provide the infrastructure that allows high-quality clinical research to take place in the NHS by increasing the opportunities for patients to take part in clinical research and ensuring that studies are carried out efficiently through help with recruitment and running of studies. The NIHR CRN awarded Service Support Costs, which is funding provided to GP practices to reimburse practices for their staff time spent on research. The award letter is in Appendix 10. I initially chose boroughs of London as they were close to UCL but when recruitment proved difficult, I expanded the study to include the boroughs of Newham, Redbridge and Barking and Dagenham.

Participating GP practices searched their patient databases for South Asian patients over the age of 50 without a recorded diagnosis of dementia and living at home. All people who met these criteria were eligible for inclusion in the study. I chose this age group as participants in the pilot testing of the intervention had suggested targeting those over the age of 50 because this group were likely to be involved in making decisions about healthcare for older family members. I also chose to target those without a known diagnosis of

dementia, because the intervention was aimed at encouraging people to seek help for memory problems and I reasoned that sending it to someone who already had a diagnosis of dementia may be insensitive and would also not be addressing whether the intervention could have an effect on attitudes to help-seeking.

9.7 Randomisation

This was a cluster randomised trial to prevent contamination within practices, with each GP practice being a cluster. I chose to cluster by practice as I reasoned that within inner city London, individuals from the same ethnic group who were registered with the same GP practice, may live quite close to each other and may interact considerably with each other, so the risk of contamination if the study was randomised by individual, might be quite high.

A researcher from UCL Division of Psychiatry who was not involved in the study used a random number generator for block randomisation of blocks of two or four practices. I intended to include roughly equal number of participants in each arm of the trial. Recruitment of GP practices was quite difficult and after the first three months of recruiting, I had recruited four GP practices. As I did not know if any more GP practices would agree to take part and I did not want to delay the study any further, I decided to randomise this first block of practices and continue trying to recruit further. Block randomisation is suitable where you wish to keep numbers roughly equal in each arm of the trial (Altman and Bland 1999) as was the case in this study.

The first block of four practices included three practices from Camden and one from Redbridge. The percentage of South Asians in the population is almost three times higher in Redbridge compared to Camden (Office for National Statistics 2007) so to equalise potential participants in each group, I decided to randomise the boroughs rather than the practices and allocate the practices in a 3:1 ratio. Following this, I had two more blocks of enrolled practices, with each block containing two practices from the same borough and these were randomised in a 1:1 ratio. This is shown in Figure 9-1 below.

	Block 1	**Block 2**	**Block 3**
Intervention	Redbridge - 1	Barking & Dagenham - 1	Camden - 1
Control	Camden - 3	Barking & Dagenham - 1	Camden - 1

Figure 9-1: Block randomisation

9.8 Blinding

As the main objective was to consider feasibility and acceptability, the study was not blinded. As I was responsible for sending out interventions to participants, I was aware of their allocation status and participants could not be blinded to their allocation due to the nature of the intervention.

9.9 Procedures

9.9.1 Identifying potential participants

I telephoned or emailed GP practices to inform them about the study and ask if they would like to enrol. Some GP practices were contacted by the CRN coordinators who sent information about the study.

My original research protocol stated that GP practices' staff would telephone potential participants to ask if they would like to take part in the study. They would then pass details of consenting participants to me. I would contact potential participants to enrol them in the study. The initial feedback from GP practices was that recruitment using this method would take up too much of the practice's time. I applied for and was granted an ethical amendment to the study (see Appendix 11 for original ethical approval and amendment) so that GP practices could send out a letter to all potential participants with an opt-in reply slip that they could fill in and return to me or they could contact me by email address or telephone number if they wished to participate. The initial information sheet which was sent to GP practices, can be found in Appendix 12.

After feedback from GP practices and discussion with my supervisors, I decided to use a small financial incentive for participants to improve recruitment. I again applied to the research ethics committee for an ethical amendment which was done at the same time as the amendment to the

procedure for contacting participants. The amendment was granted and the initial letter sent out by GPs stated that participants in the study would be given £20 of high street vouchers. This letter is in Appendix 13.

I used Docmail, an independent mailing company to mail all potential participants in participating GP practices the standard letter informing them about the study and asking them to either get in touch with me using the email address or telephone number listed on the letter or to return the opt-in slip if they were interested in taking part in the study. The company liaised with GP practices directly and asked them to upload names and contact details for potential participants onto their website. They then merged this information with the letter I had written and mailed it out with a Freepost envelope for potential participants to mail back their reply slips.

9.9.2 Contacting potential participants

Once I received the reply slips or phone calls/emails from interested individuals, I contacted respondents individually, explained more about the study over the telephone/email and then sent them the Participant Information Sheet (PIS) which gives more detail about the study (see Appendix 14). I gave potential participants at least 24 hours to read the information sheet when I had sent it by email, and at least a week if I had sent it by post. I contacted potential participants after they had a chance to read the information sheet and asked if they wished to take part in the study. If they did, I posted the intervention to intervention group participants. If at the initial interview participants did not

recall receiving the intervention, I re-sent it around two weeks prior to their follow-up date. Control group participants received no additional information.

I classified people as “non-responders” if I was unable to arrange to meet with them to obtain consent and complete the questionnaire after at least three attempts to contact them using at least two different contact methods, such as written letter/telephone message/email or text message. If potential participants declined to take part in the study after receiving further information, I classified these as “refusals” and noted the reasons for not wishing to participate where these were given by the individual.

I made an appointment with all potential participants who agreed to see me to obtain consent and complete the initial interview. I offered participants the choice of an interview in their own homes, the Division of Psychiatry or another location such as a restaurant or café. I ensured I had my mobile phone with me as a safety precaution.

I made at least three attempts to contact consented participants for follow-up using as many different methods of communication as possible.

9.10 Assessments

9.10.1 First visit/T1 (after intervention receipt)

At the initial interview, I checked participants’ understanding of the study and gave them an opportunity to ask questions. Participants then filled in a consent

form (see Appendix 15) and self-completed the initial questionnaire. The questionnaire started with a vignette describing someone with significant memory problems suggestive of a dementia, as used in the focus group discussion (see box 5-1). After reading the vignette, participants are asked to imagine they have similar problems and then answer the questions about help-seeking and provide information about themselves. A copy of the questionnaire is in Appendix 16.

9.10.2 Follow-up/T2 (after the first visit)

Three months after the initial visit, I contacted participants and asked them to complete outcomes face-to-face, by post or email, according to their personal preference. A copy of the follow-up questionnaire is in Appendix 17.

9.11 Measures

At the initial interview, I recorded the date I had received initial contact from participants, the date I had sent them the information sheet and intervention (if in the intervention group), as well as dates and locations of the initial interview. I also recorded dates of follow-up interviews or reasons given by participants for not continuing in the study, if they provided these.

I asked participants questions about:

- Demographics (including socioeconomic status and other potentially important confounders).

- Whether they recalled receiving information about dementia from their GP
- What thoughts they had about the materials they viewed, including any comments about the material they saw and if it should be changed.

At the 3 month interview, I asked participants

- Whether there had been any changes in their personal circumstances since the previous appointment.

At the initial interview and follow-up interview 3 months later, participants also completed primary and secondary outcomes.

9.11.1 Primary outcomes

The primary outcomes for this pilot study were:

1. Feasibility of recruitment. I recorded the numbers of participants who enrolled in the study after agreeing to receive further information about it.

2. Acceptability of the intervention. Participants were asked to rate the acceptability of receiving the intervention from 1 (totally unacceptable) to 5 (totally acceptable).

3. Rates of follow-up. I recorded whether people who were initially contacted by GPs responded to the initial invitation, completed the initial questionnaire and completed three month outcomes.

9.11.2 Secondary outcomes

9.11.2.1 Differences in the Behavioural Intention subscale of the Attitudes of People from Ethnic Minorities to Help-seeking for Dementia (APEND) questionnaire

The APEND questionnaire measures intention to seek help for memory problems (Behavioural Intention) as well as Subjective Norms, Behavioural Attitude and Perceived Behavioural Control which are all theoretical constructs thoughts to underlie intention and influence action, according to the Theory of Planned Behaviour (see section 8.3.1.) The possible range for scores on the Behavioural Intention subscale of the APEND questionnaire was -9 to +9. This subscale measures a person's intention to carry out a particular behaviour, in this case, seeking help for memory problems. This subscale was chosen as one of the main outcomes because of its high correlation with actual behaviour (Ajzen 1991) so it was felt to be the best estimator of what people would do if they developed memory problems in reality.

We devised and validated the APEND questionnaire. This work was led by another researcher (Julia Hailstone) as her Doctorate in Clinical Psychology thesis, alongside my qualitative work described earlier in this thesis. I was involved in recruiting participants for this study, generating initial questions for

inclusion and modification of the questionnaire based on emerging results. JH led the statistical analysis of the questionnaire items and validated the final questionnaire using the answers of 51 South Asian people with varied socio-demographic characteristics (Hailstone et al. 2016) (see Appendix 18 for published paper). We based the questionnaire on the Theory of Planned Behaviour (see section 8.3.1). The questions included directly measure each of the constructs of this theory (behavioural intention, behavioural attitudes, subjective norms and perceived behavioural control) while other questions address these constructs indirectly for validation. JH led the development and modification of the questionnaire using methods described in the literature (Ajzen I. 2002).

The final questionnaire consists of 19 questions all scored on a Likert scale from one (indicating strong disagreement) to seven (indicating strong agreement). A score of four on any question indicated neutrality. There are three questions each measuring intention to seek help for dementia and perceived behavioural control and two questions each measuring behavioural attitudes and subjective norms. There are a further nine questions measuring behavioural beliefs, outcome evaluation and motivation to comply which are indirect measures used to validate the main constructs. The sum of the 10 questions directly measuring TPB constructs was 30. In the validation sample which has been published, all direct attitude and intention ratings were negatively skewed, indicating favourable help-seeking attitudes and intentions.

In this group, the combined model explained 77% of the variance in willingness to seek help for memory problems and anticipated social pressure from important others was most strongly associated with willingness to seek help (Hailstone et al. 2016).

9.11.2.2 The Dementia Knowledge Questionnaire

The Dementia Knowledge Questionnaire (DKQ) (Graham et al. 1997) was a pre-existing measure assessing knowledge of dementia. It asks about aetiology, epidemiology, symptoms and treatment of the disease and is scored out of 19, with higher scores indicating greater knowledge about dementia. I chose it as it has been used and validated in South Asians previously (Purandare et al. 2007). This study found South Asians scored significantly less, on average three points, on the scale than the White UK participants. There is no published literature on its standard deviation but scores on it are not normally distributed. It has been validated in family carers of people with dementia (Graham et al. 1997). The DKQ was also administered to participants who completed the APEND questionnaire in the validation study and in that group of participants, the average score was 8.9 (Hailstone et al. 2016) which was higher than the median of 3 and 25th-75th percentile of 2-5 found in a previous sample of South Asians (Purandare et al. 2007) and it was not related to willingness to seek help for memory problems or with attitudes that predicted help-seeking. The APEND and DKQ have been incorporated into my study questionnaire which can be seen in Appendix 16 and 17.

9.12 Sample size

As this was a pilot RCT with outcomes being acceptability and feasibility, I based the power calculation on these outcomes. I was aiming for acceptability and feasibility of at least 70% and a follow up rate of 80%.

I calculated that with 40 participants in the intervention group I would be able to estimate the expected acceptability and feasibility of 70% with a 95% confidence interval that the true value lay between 53% to 83%.

With a total sample size of 80 I would be able to estimate the expected 80% follow up rate with a 95% confidence interval that the true value lay between 70% to 88%. I therefore aimed to recruit around 80 participants with 40 in each arm in order to obtain this level of precision.

9.13 Analysis

I used SPSS version 23.0 for all statistical analyses and pre-specified and agreed an analysis plan with my supervisors before data collection was complete.

9.13.1 Demographic characteristics of participants:

I entered variables such as age and years of education into the SPSS database as they were written by participants. For categorical variables, I assigned an integer to each category and kept records of the numbers used. I then entered these numbers into the database instead of entering text as

written by participants. I used the Standard Occupational Classification (Office for National Statistics 2010) to code occupations into numbers. This uses the number one to denote those in managerial positions, the number two to denote those in professional occupations and so on until those in elementary or unskilled occupations are grouped under the number nine.

I compared characteristics between control and intervention group and described these.

9.13.2 Primary outcomes measures:

I calculated initial response rate as the number of people who responded to the initial invitation divided by the number of invitation letters sent out by GP practices.

I calculated the proportion of successfully recruited participants as the number who completed an initial questionnaire divided by the total number who initially expressed an interest in the study (including the non-responders and those who refused).

Participants were asked to rate the acceptability of receiving the intervention from 1 (totally unacceptable) to 5 (totally acceptable). I calculated the percentage of participants in the intervention group who rated acceptability as four or five on the Likert scale.

I calculated the proportion successfully followed-up by dividing the number of people who completed a both an initial and follow-up questionnaire by those who just completed an initial questionnaire.

I noted free text comments from participants about the intervention and if there were any changes they would recommend.

9.13.3 Secondary outcome measures:

In line with other studies and published guidance on scoring the questionnaire, I re-coded my data so that the scores on each question on the APEND questionnaire ranged from minus three for extreme disagreement, through zero indicating neutrality and up to plus three for extreme agreement (Francis et al. 2004). I then added up all scores for each construct and used these as the main outcomes for further analysis.

9.13.3.1 Analytic tests

I had two data collection time points, so therefore had repeated numerical data from the same individuals. The linear mixed model (Laird and Ware 1982) is widely used for the analysis of longitudinal continuous data because it takes correlation between scores on a measure from the same individual into account and the maximum likelihood estimators are easily obtained using standard software. In longitudinal studies, linear mixed models provide estimates of fixed effects, which are factors that affect all groups in the study and have an effect on the main outcome measure over time. These fixed

effects can be adjusted for covariates which might confound the association. It also estimates random effects, which accounts for intra-subject correlation. As with most statistical models, there are a variety of assumptions that are specified before the analysis is undertaken but previous studies have shown that the linear mixed model is robust to violations of its underlying assumptions, including ones on normality of distribution of the errors, especially if the sample size is at least 50 (Jacqmin-Gadda et al. 2007).

I used linear mixed models analysis with intention to seek help, as measured on the APEND questionnaire, as the main outcome for reasons specified earlier (see Section 8.3.1).

I also conducted mixed models analysis with the subjective norms subscale on the APEND questionnaire as a separate outcome as this was most likely to be associated with an increased score on intention to seek help in our validation sample and would potentially explain the mechanism for difference in intention to seek help. I included all potentially important confounders such as age, gender, and education as covariates. The primary model included time and group (i.e. intervention or control) as fixed factors with demographic factors as covariates and a random effect for participant.

I compared mean scores on the DKQ at initial visit and follow-up using the t-test.

In the next chapter I present results from this trial.

10 : Pilot cluster randomised controlled trial - Results

10.1 Recruitment

Figure 10-1 shows the CONSORT flow diagram of recruitment. Eight GP practices agreed to be in the study out of 16 contacted.

1462 South Asian practice patients were identified by the practices and sent letters asking them to contact me or their surgery if they wished to express an interest in participating in a study. 102/1462 (7%) replied. Of the initial 102 respondents; 78 (76.5%) took part. Of the 24 who did not take part, I classed 14 as non-responders, as after receiving the information sheet they agreed to take part but then did not respond to further attempts to contact them (n=8), or I was unable to speak to them at all (n=6). Nine out of 88 (10.2%) of those to whom I sent information sheets did not consent to take part. Of these, one was too unwell to take part, four people said they were too busy and four did not give a reason. One person was not suitable for inclusion because she lacked capacity to consent to the study due to advanced dementia.

Figure 10-1: CONSORT flow diagram

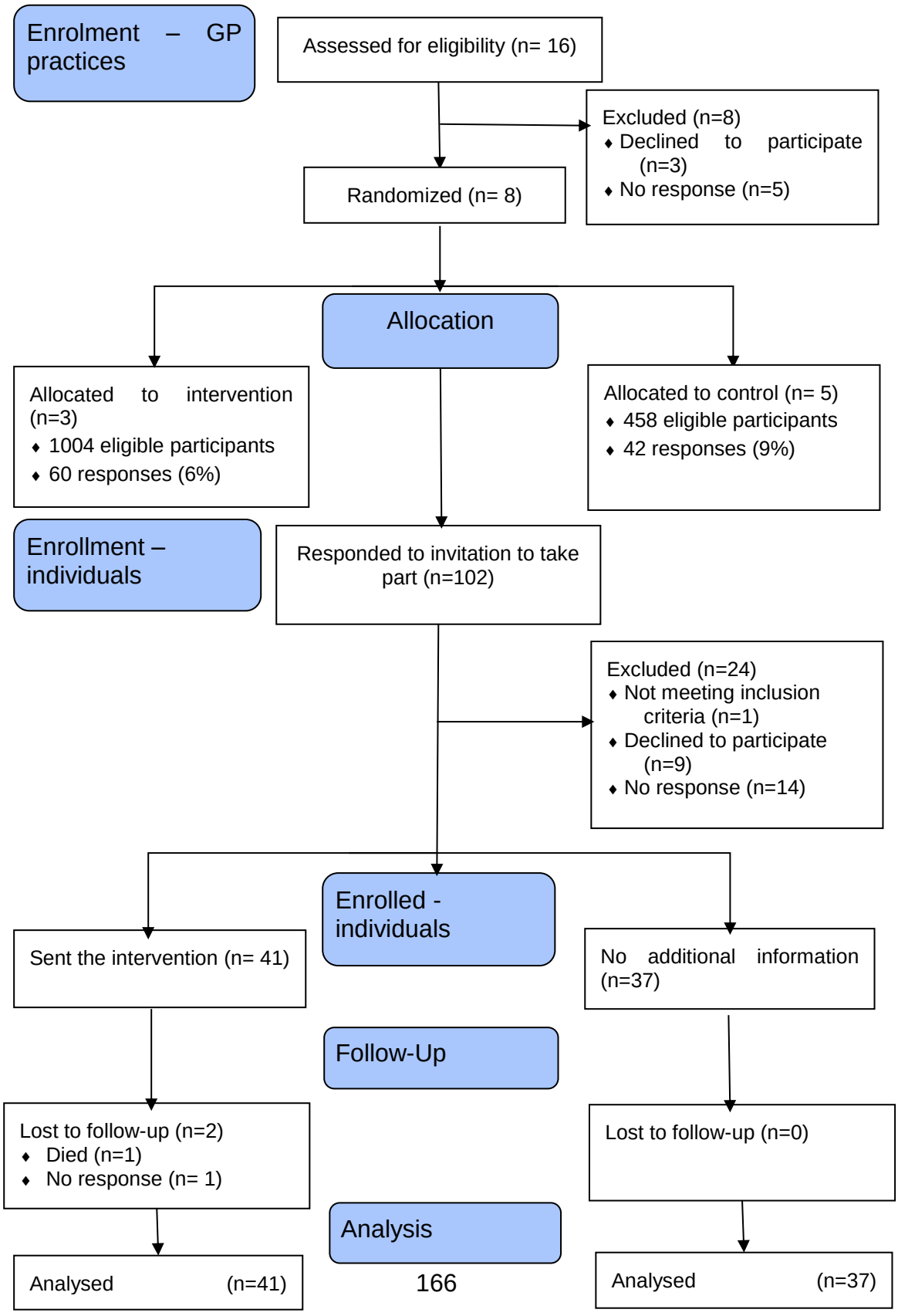

Table 10-1 shows the area of recruitment (Clinical Commissioning Group) and sex of the participants who agreed to be in the study compared to those who did not. People from Redbridge enrolled in the study less commonly than those in other areas and non-participants were more often male.

Table 10-1: Characteristics of people who responded to the invitation to participate and completed first visit measures compared to those who did not.

Area of recruitment (CCG)	**All participants n =78** **n(%)**	**Non participants n=24** **n(%) or mean**
Camden	33(42)	5(21)
Redbridge	26(33)	15(62)
Barking & Dagenham	19(25)	4(17)
Sex		
Male	39(50)	14(58)
Total	**78**	**24**

10.2 Characteristics of participants

10.2.1 Demographics

Table 10-2, 10-3 and Table 10-4 show the demographic characteristics of people in the intervention and control groups. Participants in the intervention and control groups were similar in age, with mean ages of around 64 years but the intervention group had a greater proportion of male participants. The majority of the control group participants were registered with GPs in inner London, whereas most of the intervention group were from greater London. This occurred because the outer London GP practices had many more South Asian patients than the inner London ones. There were higher number of eligible participants in the intervention group.

Both groups had a majority of Indian participants (59%). The intervention group only included Indian and Pakistani participants, whereas the control group had a wider range of self-defined ethnicities. Both groups had a similar range of religions. Most of the participants were retired and there was a similar range of occupations although the control group included more people who had worked in unskilled occupations. The intervention group had lived fewer years in the UK, spent less years in full-time education and were more likely to need an interpreter.

Table 10-2: Demographic characteristics of participants at T1: age, sex, ethnicity and religion

Characteristic		**Intervention (n=41) N(%)**	**Control (n=37) N(%)**	**Characteristic**		**Intervention (n=41) N(%)**	**Control (n=37) N(%)**
Mean age (S.D.)		64.5 (10.0)	63.6 (10.6)	**Ethnicity**	Mixed	0	1 (3)
Sex	Male	23 (56)	16 (43)		Other	0	1 (3)
CCG	Camden	3 (7)	30 (81)	**Religion**	Islam	18 (44)	14 (38)
	Redbridge	26 (64)	0 (0)		Hinduism	14 (34)	12 (32)
	Barking and Dagenham	12 (29)	7 (19)		Christianity	2 (5)	6 (16)
Ethnicity	Indian	24 (59)	22 (59)		Sikhism	2 (5)	1 (3)
	Pakistani	17 (41)	2 (5)		Other	5 (12)	4 (11)
	Bangladeshi	0	11 (30)				

Table 10-3: Marital status, education and employment status of participants at T1

Characteristic		**Intervention (n=41)N(%)**	**Control (n=37)N(%)**	**Characteristic**		**Intervention (n=41)N(%)**	**Control (n=37)N(%)**
Marital status	Married/living with partner	35 (86)	24 (65)	**Employment status**	Employed	10 (24)	8 (22)
	Single	1 (2)	4 (11)		Retired	17 (42)	21 (56)
	Divorced	0 (0)	3 (8)		Unemployed	14 (34)	8 (22)
	Separated	1 (2)	1 (3)	**Mean years in UK (S.D.)**		34.5 (13.8)	39.3 (13.9)
	Widowed	4 (10)	5 (13)				
Interpreter needed		14 (34)	4 (11)				
Mean age left full-time education (S.D.)		18.3 (5.8)	21.3 (6.5)				
Mean years in UK (S.D.)		34.5 (13.8)	39.3 (13.9)				

Table 10-4: Type of employment

Characteristic		**Intervention (n=41)N(%)**	**Control (n=37)N(%)**
Type of employment	Housewife	7 (17)	4 (11)
	Managers, directors and senior officials	6 (15)	6 (16)
	Professional occupations	8 (21)	7 (19)
	Associate professional and technical occupations	1 (2)	3 (8)
	Administrative /secretarial occupations	3 (7)	5 (14)
	Skilled trades occupations	3 (7)	2 (5)
	Caring, leisure and other service occupations	2 (5)	2 (5)
	Sales and customer service occupations	3 (7)	1 (3)
	Process, plant and machine operatives	6 (14)	1 (3)
	Elementary/unskilled occupations	2 (5)	6 (16)

10.2.2 Experience of dementia

People in the control group knew more people with dementia and had cared for and worked with more people with dementia but were less likely to have consulted their GP for memory problems. Table 10-5 shows the experiences of dementia and memory problems in those in the intervention versus control groups.

Table 10-5: Experiences of dementia

	Intervention (N=41) **N (%)**	**Control (N=37)** **N (%)**
Someone they knew well had dementia	14 (34)	19 (51)
Cared for someone with dementia	4 (10)	6 (16)
Worked with people with dementia	4 (10)	6 (16)
Had seen their own doctor for memory problems	6 (15)	2 (5)

10.2.3 Primary outcomes

1. Feasibility of recruitment.

78 /102 (76%; 95% Confidence Interval 67 to 84%) people who expressed an interest in the study consented to take part in the study and completed an initial questionnaire.

2. Acceptability of the intervention.

Out of 41 participants in the intervention group, 37 (90%; 95% Confidence Interval 77 to 96%) rated the intervention as either “somewhat acceptable” (6/37) or “completely acceptable” (31/37; 83.8%). One person (2%) rated the items as “neither acceptable nor unacceptable” and three other participants did not answer this question.

3. Rates of follow-up.

Out of 78 people who completed the first visit measures, 76 (97%; 95% Confidence Interval 91 to 99%) completed the final follow-up questionnaires. One participant died of a myocardial infarction before her follow-up date and one participant was not contactable for completion of follow-up.

The first visit (T1) was a mean of six weeks after sending the intervention (range < 1 week to 12 weeks) in the intervention group and within two weeks after initial contact for the control group. Follow-up (T2) was a mean of 13 weeks after the first visit with a range of 10 to 21 weeks and a standard deviation of 2.8 weeks.

10.2.4 Remembering the intervention

Most intervention group participants recalled getting the intervention in the post (32/41 = 78%) but nine people did not recall receiving it and I re-sent the intervention to these participants.

10.2.5 Viewing the intervention

Only 17 people (41%) said they had looked at the intervention. 23 had not and one person did not answer this question. Of these 17 people, 10 looked only at the leaflet, three only looked at the DVD and four people looked at both leaflet and DVD.

10.2.6 Comments

There were 33 comments from the four questions asking:

- what participants thought of the materials,
- what they thought the key messages were
- any changes they would recommend
- any other comments

Some of the comments were simply recording that people had not looked at the materials or could not remember them. Just over half of the comments stated that the information was “good” or “useful” for increasing awareness about dementia. Some participants had identified key messages such as where to get help for dementia, that help is available and the importance of monitoring memory and to inform your family doctor at the earliest opportunity if you have concerns about your memory. These are all described in more detail below.

10.2.6.1 What participants thought about the materials

14 participants completed this section. Of these, three said they could not remember what they had seen. Of the remainder, four said the materials were "good" or "helpful" or "useful" without any further details. Five participants said the intervention was informative, for example saying,

> *"It is very effective to understand about dementia" and*
> *"Very informative, useful to keep in mind".*

Some participants commented on its relevance to their own lives, for current concerns or for bearing in mind for themselves in the future, for example saying,

> *"It is good to know if it happens in my life" and "it was helpful for future".*

One participant commented that it made her feel she should get a friend of hers to see a doctor about her memory.

10.2.6.2 What participants thought the key messages were

13 participants filled in this section. Of these, two commented that they did not know what the key messages were and one said they could not remember. One person wrote "awareness" with no further clarification and another just said the intervention was useful. Three participants said the key messages were about the availability of help and that it is possible to do something about dementia, for example,

> *"If you suffer in future, where to find help" and*

"There are ways to help with dementia, Alzheimer's".

Three participants noted the importance of seeing your doctor if you noticed memory problems, for example, saying,

"To see my doctor at the earliest for a diagnosis" and

"Keep your memory healthy. If worried about your memory go to your doctor".

Two other participants noted the importance of monitoring your memory for any changes, for example,

"Keep an eye on yourself (your memory)".

10.2.6.3 Recommended changes

Only two people commented, suggesting only that there should be *"more details and information"* and changes should be made *"if new important information comes up"*.

10.2.6.4 Other comments

Only three people made comments. They said the intervention was "good" and it was *"good to increase awareness"*. One person wrote *"the importance of eliminating dementia"*.

10.2.7 Secondary outcomes

10.2.7.1 1. APEND questionnaire

Scores on all subscales were similar in both groups at first assessment after the intervention and increased during the trial. The mean scores and standard

deviations of all subscales are shown in Table 10-6 and as shown, they are similar in both groups.

Table 10-6: Scores on subscales of APEND questionnaire and total scores

Subscale	**Intervention Mean (S.D.)**	**Control Mean (S.D.)**
Intention (T1)	6.0 (5.1)	6.5 (3.4)
Intention (T2)	6.2 (5.2)	6.9 (3.0)
Behavioural attitudes (T1)	3.5 (3.6)	4.4 (2.6)
Behavioural attitudes (T2)	3.4 (3.8)	4.1 (3.2)
Subjective Norms (T1)	4.0 (2.7)	4.4 (2.1)
Subjective Norms (T2)	4.6 (2.3)	4.2 (2.4)
Perceived behavioural control (T1)	5.0 (4.2)	6.1 (3.1)
Perceived behavioural control (T2)	6.1 (4.2)	6.1 (3.2)
Total score (T1)	18.5 (13.8)	21.4 (9.1)
Total score (T2)	20.3 (13.3)	21.3 (9.2)

Linear mixed models with a fixed effect for time and the intervention and a random effect for subject, adjusted for sex, age and education showed the following:

1. Behavioural Intention scores did not differ significantly between intervention and control groups over time (Parameter estimate -0.5, 95% CI -2.2 to 1.2, p=0.56). None of the other covariates significantly affected the score either.
2. Subjective Norm scores did not differ significantly between intervention and control groups over time (Parameter estimate -0.01, 95% CI -0.95 to 0.93, p=0.99). There were no significant effects on score of any of the other covariates.

10.2.7.1.1 Post-hoc analysis

I compared mean scores on Behavioural Intention between control group and intervention but only including those participants in the intervention group who said they had viewed the intervention. I chose this comparison because of the low percentage of people who had said they looked at the intervention and an intervention cannot have an effect unless it is engaged with in some way. Although this was not an intention to treat analysis it gave an idea as to the effect the intervention might have in the best of circumstances. I used the Mann Whitney U test as the subscale scores were not normally distributed. In this sub-group, the mean difference at T1 on the Intention subscale was 1.5 points higher in the intervention group (U= 212.5, Z= -2.1, p=0.037).

In order to explore whether this finding could be due to confounders I compared those who said they viewed the intervention with those who said they did not and found no significant differences between the two groups on

age, sex, years of education, occupational classification, number of years in the UK or experience of dementia.

10.2.7.2 2. Dementia Knowledge Questionnaire

The DKQ was normally distributed at both time points. The mean score on the DKQ was higher in the control group at both time points (Mean 6.8/19 vs 5.3 at T1and 7.9 vs 6.6 at follow-up) but this was only statistically significant at the first time point (Mean difference 1.6 points, p=0.043) and both groups of scores increased from the first to second time points.

11 : Discussion

This study is the first to design and test an intervention aimed at encouraging help-seeking for dementia earlier in the South Asian population. All pre-stated criteria for feasibility, acceptability of the intervention and follow-up rates were met in this feasibility and acceptability trial. Therefore this intervention is acceptable and a full-scale RCT would be possible in terms of feasibility specified here, i.e. recruitment and follow-up. There were no differences between intervention and control groups on APEND questionnaire sub-scale scores but the study was not powered to examine this outcome.

The study has added to the literature on encouraging diagnosis as well as providing some insights into recruitment in primary care, designing complex interventions and disseminating information. In this chapter I summarise the findings of my systematic review, observational study and qualitative study. I then discuss the findings of my RCT and list the respective strengths and limitations of all the studies in this thesis.

11.1 Systematic review findings

I found that educating GPs about dementia and assisting them in making dementia diagnoses increased the number of suspected dementia cases but not the number of confirmed diagnoses. Greater provision of memory services was associated with an increase in the numbers of people diagnosed with dementia and there was some indication that memory services diagnosed dementia at an earlier stage compared to standard psychiatric services.

Untargeted leaflet campaigns of the general population to educate them about dementia had no impact on diagnosis of dementia.

11.2 Observational study findings

I found a temporal link between launch of the National Dementia Strategy and an increase in numbers of dementia diagnoses, dementia diagnosis rates and prescriptions for anti-dementia medications. This suggests that policy-level interventions can have an impact on dementia diagnosis but as this was a retrospective study, I cannot assume causality. In addition, there is no way of ascertaining the mechanism of change.

11.3 Qualitative study findings

The study explored barriers to help-seeking for dementia in more detail and found that people may be reluctant to seek help because of uncertainty about the threshold for help-seeking, as well as concerns about stigma and the relinquishing of familial responsibility. Participants suggested that an intervention should give information about key symptoms which should lead to help seeking and how help-seeking could be beneficial to the person with dementia, as well as the family by enabling them to allay their fears and to live as well as possible for as long as possible.

Participants felt the information should come from a trustworthy source, such as the NHS and should be presented as a story rather than purely clinical information. Visual presentation of the information was also desirable.

11.4 RCT study findings

11.4.1 Outcomes

I successfully met all my pre-specified targets for acceptability, recruitment and follow-up rates. The study also produced some interesting results in secondary and additional outcomes.

11.4.2 Attitudes to help-seeking

The study was not powered to detect differences on the APEND questionnaire subscales and did not find any differences in intention to seek help for memory problems or subjective norms regarding help-seeking. In fact, the data suggested that people from the control group may have viewed help-seeking more favourably and this could be explained by higher levels of education and knowledge compared to the intervention group. However, my post-hoc analysis findings of an increase in score on the intention subscale of the APEND in those who viewed the intervention compared to the control group is promising. These results have to be viewed with caution as they were an unplanned analysis and the chances of a spurious result increase with the number of statistical analyses. However, the findings were not explained by measured confounders and make logical sense as we cannot expect to influence attitudes with any intervention unless people engage with the intervention in some way. This highlighted problems with the delivery of the intervention which I address further below.

None of the other APEND subscales were any different in the intervention participants who looked at the intervention compared to the control group.

11.4.3 Knowledge about dementia

There were also no differences on the DKQ between the two groups and scores over time increased in both groups.

11.4.4 Mechanism of change

It is not clear why intention to seek help was higher in the intervention group in those who viewed the intervention, as there were no differences between the groups on knowledge, behavioural attitudes, subjective norms or perceived behavioural control. It may be that the mechanism of change was not detected on subscales due to a lack of power, or that the change is effected through another mechanism that was not measured by the APEND scale. Or the finding may be spurious and there is no real difference in the scores.

Scores on both the APEND and DKQ increased over time, which may be an effect of being in the trial and having greater awareness of dementia and that medical help may be appropriate for memory symptoms.

11.4.5 Help-seeking for dementia

It was interesting that three times as many people in the intervention group as the control had seen their GP regarding memory problems before my initial visit. I did not ask whether this visit occurred before or after receiving the intervention so cannot draw conclusions as to the effect of the intervention on

help-seeking itself but the difference is not due to age as both groups were similar in their ages. It is also unlikely to be due to greater exposure to dementia as people in the control group were more likely to know someone with dementia.

11.4.6 Key messages of the intervention

Many people seemed to understand that the leaflet was aimed at improving knowledge about dementia and also understood that the key messages were about seeking help if you became concerned about your memory and that help was available for dementia. Not many people filled in these free text sections so it is hard to draw firm conclusions but the results are promising.

11.4.7 Adverse effects

I did not directly ask about any adverse effects of the intervention. It seems likely, based on its high acceptability that people were not distressed at receiving the intervention. The participant information sheet also included information about the possibility of becoming distressed during the study and had advice about what to do if that happened which was an additional precaution that could have identified any problems. However, in other studies of this nature, it may be preferable to directly ask about any negative effects of being in the study or receiving materials.

Below I discuss the findings and strengths and limitations of all studies in this thesis further.

11.5 Systematic review strengths and limitations

11.5.1 Strengths

The search terms and databases used were highly inclusive so I am unlikely to have missed any relevant interventions. Screening of titles and abstracts was carried out my two people independently, as was quality rating and data extraction.

11.5.2 Limitations

The interventions were highly heterogeneous, so I could not meta-analyse data. Some of the “interventions” were policy changes or secular trends so changes in number of people diagnosed with dementia, and stage/severity at diagnosis, could be the result of interacting increases in awareness of dementia, market forces/public demand, and medical specialisation.

Many of the studies were probably underpowered, and most were of low or fair quality. Many study protocols deviated significantly from routine practice, so implementation would be costly and there was no evidence whether changes generalised after the intervention. Studies did not report on adherence to the research protocol and I did not assess fidelity to protocol as part of the quality assessment. However, as most of the interventions were a one-off event such as an educational session, this is unlikely to be relevant. None of the studies included information about intervention costs so I could not evaluate cost effectiveness. All of the included studies were conducted in relatively affluent Western countries with well-established medical infrastructures and most were

in urban settings. All targeted the general population apart from one study in the South Asian community, so I do not know how generalisable the findings would be to other countries or ethnic groups.

11.6 Observational study strengths and limitations

11.6.1 Strengths

It is important to assess the effect of government policy to ensure the best use of resources in managing dementia and other illnesses and this was the first study in the UK to do so.

The QOF provides a financial incentive for GP practices to create and maintain a register of patients with dementia. It is a voluntary reward scheme and there has been some debate about whether it provides an accurate estimate of numbers diagnosed with dementia. I tested its validity and found the QOF data to be highly correlated with prescriptions for anti-dementia medication, indicating that it is a valid measure of the numbers of people diagnosed with dementia. There is still a significant amount of variance in prescription which is unexplained by diagnosis rate. However, areas which had low diagnosis rates did not have higher prescription rates per person diagnosed with dementia, indicating that there is not a systematic omission of people with dementia from the QOF register in these areas. Although anti-dementia drugs are recommended in the UK across all the dementia severity ranges and there is no reason to think that the proportion of people with Alzheimer's dementia

varies across areas; I do not know whether some practitioners prescribe in different ways. However, my analysis found no systematic pattern in the PCTs with low dementia diagnosis percentages and therefore suggests that the low rates are not accounted for only by a failure to record diagnosis.

11.6.2 Limitations

Due to the nature of the intervention being studied, I could only establish associations and temporal links between the launch of the National Dementia Strategy (NDS) and outcomes. It may be that there is another explanation for the changes, including a change in peoples' perceptions about dementia. This could account both for the launch of the NDS and the change in diagnosis and prescription rates. Also, the NDS is a policy change with a wide remit and regional variation in its application. It is therefore difficult to say with any certainty which aspect of the NDS may account for the changes in outcomes we have seen. Finally, all the data was retrospective and not specifically collected with the aim of assessing the impact of the NDS, therefore systematic error cannot be ruled out.

Although I did not have any data on the timeliness of the dementia diagnoses being made, if the increase in dementia diagnosis is due to more diagnoses being made in memory services, these diagnoses are likely to be more timely (Luce et al. 2001).

11.7 Qualitative study strengths and limitations

11.7.1 Strengths

This was a relatively large qualitative study with good variation in participant demographic characteristics. Sampling was purposive for characteristics which could have an impact on attitudes to help-seeking for dementia and continued until theoretical saturation was reached. Data analysis was iterative and carried out independently by two researchers to maximise the yield of themes and concepts.

The use of a case vignette and group discussions gave detailed and varied accounts of the help-seeking process. Individual interviews, particularly with professionals with experience of working with people with dementia, provided interesting insights based on personal experiences of working within the South Asian community. Overlap with previously identified barriers to help-seeking in dementia in minority ethnic groups suggests validity of the findings.

There was some overlap in the findings from my study and another study looking at help-seeking for dementia in the Black community (Berwald et al. 2016). However, although there were some similar concerns and barriers to help-seeking in the South Asian and Black participants, there were enough differences in expressed views and preferences for the intervention design which supported the idea that I was creating a culturally appropriate, unique and targeted intervention.

11.7.2 Limitations

While this relatively large qualitative study gave rich in-depth information about the views of 53 community members, it will not necessarily cover the views of that whole community, particularly as all participants were from in and around London.

I did not find any differences in expressed opinions among participants from different religious and cultural backgrounds or from first versus second generation South Asians. This may be due to the sample being too small or not reflecting the diversity of London's South Asian population.

As I was asking people about a hypothetical case, it may be that their opinions would change should they face the same situation in reality.

11.8 RCT strengths and limitations

11.8.1 Recruitment challenges

11.8.1.1 Difficulty recruiting in primary care

I aimed to recruit 40 participants in the intervention arm and 80 people overall. I met the former but not the latter target.

Most people who had expressed an interest in the study consented to enrol in it but the initial response rate from people sent a letter by their GP was only 7%.

Recruitment to clinical trials is difficult across all patient settings, with one study looking at data from 114 trials finding that less than a third of all clinical trials in the UK achieved their stated recruitment target and over half of trials required an extension to the duration of the project in order to meet recruitment targets (McDonald et al. 2006). Recruitment figures are similar in trials exclusively based in primary care (Bower et al. 2007). One study found that only 7.8% of GPs approached for participation in a clinical trial agreed to start recruiting patients (Tognoni et al. 1991). My study had a higher response rate of 50% from GP practices themselves, probably because there was no need for GPs themselves to recruit or consent patients. Previous research has shown that patients pay attention to correspondence from their GPs (Robb et al. 2010). In that study, 62% of eligible patients responded to their GP letter but that study involved GPs writing to eligible patients to attend for flexible sigmoidoscopy, so was directly related to the patients' clinical care and was relevant to them due to their age and risk factors. My study was very different as it was an invitation to take part in a research study with no direct relevance to the person's daily life or clinical problems.

A response rate of 7% from people who were mailed the invitation letters is in line with previous similar studies as outlined above, but is low and were a full-scale trial to be designed using the feasibility parameters I used in this pilot trial, it would be difficult to recruit participants in sufficient numbers. It may have been preferable to define feasibility in terms of an initial response rate from

participants rather than the percent consenting after an initial expression of interest.

11.8.1.2 Language barriers

I became increasingly cognisant of the impact of my own personal attributes during recruitment. Potential participants filled in the opt-in form or emailed me in English but often when I telephoned to make an appointment, I became aware that the person on the telephone was not confident in their use of English and had difficulty understanding my explanations and requests. On these occasions I was able to speak to them in either Hindi or Bengali and explain my reasons for calling and make an appointment to see them to go through the information sheet and consent process. This made me wonder whether recruitment would have been less successful if the recruiter was not able to converse in South Asian languages. I also wondered whether potential participants would have been as accepting of participation if I had not been South Asian myself or a doctor. My ethnicity and profession would have been obvious from information sheets and letters and could have influenced participants' responses. These assumptions are untested but it seems likely that at the least my ethnicity and profession are not a disadvantage.

11.8.2 Sample bias

I have no way of knowing the characteristics of people who did not respond or comparing them to those who did so there is the possibility that the people who responded to the initial invitation were in some ways different from those who

did not. They might have been more interested in research or perhaps more educated, which could mean any effects of the intervention might have been reduced due to selection bias.

11.8.3 Randomisation – Demographics

An independent researcher carried out the randomisation and I used block randomisation and considered numbers of potentially eligible participants in different areas, in order to try and equalise the numbers of eligible participants in each arm of the trial. This meant that more GP practices were in the control group although the numbers of eligible participants were still lower. The response rate from the intervention practices was lower than the control practices initially (6% versus 10%) and this equalised the numbers of participants in each arm. Randomisation in this way equalised the numbers of participants in each group and participants were demographically different between groups, except in age, particularly with regards to education. The control group was generally better educated and less likely to need an interpreter. This could account for the more favourable attitudes to help-seeking on the APEND and the higher scores on the DKQ, as higher scores on the latter have in the past been found to be associated with higher levels of education (Hailstone et al. 2016). I may have been able to avoid this if I had been able to recruit more practices and match them by area but this would have required more resources to do so. A larger study would have been less likely to find such unequal distribution.

11.8.4 Using the intervention

Less than half of those sent the intervention said they had looked at it. This has implications for assessing the acceptability of the intervention as well as the feasibility of conducting a full-scale trial. The lack of engagement with the intervention was despite it being sent with a letter from their GP advising them to look at it. The GP letter stated that the GP had no concerns about the recipient's memory and stated the aim of the enclosed material was to promote awareness. This was necessary to avoid causing alarm in patients receiving the letter but also highlighted the fact that the enclosed material was not relevant to them.

Very few people watched the DVD, with some participants commenting to me that they did not have a DVD player and were not confident enough with technology to watch it on a computer. The leaflet was more easily accessible but was only available in English and Bengali. As many of the participants in the intervention group needed an interpreter and were less educated, the English leaflet was likely to be more difficult for them to read and a lack of Bengali participants in the intervention group meant that the Bengali leaflet would also have been redundant. An Urdu or Punjabi leaflet for this group would have been more appropriate but it was not possible to generate one given the limited timescale and resources of the study. Another way of getting people to watch the video might have been to include a link to it on the GP letter or leaflet but it is difficult to know whether recipients would have found this use of technology easier than the DVD.

Although the intervention was enclosed with a letter on GP headed paper, the envelope was addressed to participants by me and had no NHS stamp on it. This might have affected the amount of attention it received.

All of the materials were sent by regular post but nine people did not recall receiving this. I re-sent the intervention to these people but did not check at the follow-up appointment if they received it. If some people did not receive the intervention at all this could have biased the results against finding an effect on the APEND scores. It is also a consideration as to whether sending items such as this in the post should be carried out by special courier to ensure the intervention is delivered. However the intervention was meant to be as close an approximation to usual practice as possible and GP letters are not usually sent by special delivery. It may also be that people who did not recall receiving the intervention had the intervention delivered but that they threw it away thinking it was a circular, someone else in the house opened the mail or that they saw the intervention but did not pay attention to it or forgot about it. Again, it is unclear how to make accessing an intervention of this type more likely as even clinically relevant letters from GPs are only responded to approximately 60% of the time (Robb et al. 2010).

11.8.5 Outcome measures

The questionnaire included a vignette of a person with memory problems suggestive of significant problems requiring further investigation. It then directed participants to imagine what they would do if they were to develop

similar problems. Previous research has shown that stated behavioural intention correlates strongly with subsequent behaviour (Ajzen 1991) but those studies have generally measured behaviour with regards to an imminent event (e.g. voting in an election) or a behaviour that participants regularly engaged in. In this study, participants had to imagine a scenario in which they developed significant memory problems and then answer questions about how they would feel about seeking help for these problems. The APEND questionnaire had the advantage of being short and easy to administer and was validated in a South Asian population. Furthermore, behavioural intention is correlated with actual behaviour and the APEND questionnaire provides insight into how behavioural change might come about. However, a limitation of the study is that I did not measure actual behaviour. Although I asked about help-seeking from a doctor, I did not ask whether this occurred before or after receiving the intervention and subjective reports of help-seeking may not be accurate. An objective measure of help-seeking such as primary care records of consultation for memory complaints or referral to a memory service could have been informative. This would have involved further ethical concerns about accessing participants' health records. It also would have been costly to access health informatics technology and the numbers of people seeking help would have been relatively small in this pilot study so any differences between the groups would have been too small to interpret meaningfully.

My hypotheses and focus in this study has been exclusively on help-seeking for dementia from a person's family doctor. This is the medical model which I

apply in my own clinical practice and one which I assume will lead to benefits for patients and their families. However, I realise that people could have other sources of help and they may not seek help from their GP in the first instance and may consult their family or community members and act accordingly, as mentioned by some of the participants in my focus groups. This does not mean they would not seek help from their doctor but that there could be other factors to consider and I did not ask about these factors in this study. However, in the UK, accessing help for dementia tends to be through a medical route so it seems reasonable to ask about this as late help-seeking could lead to undesirable outcomes, in the absence of any other formalised care provision here.

11.8.6 Observer bias

This was an unblinded study so I was aware of allocation status. Although participants self-completed the questionnaires, my awareness of what group they were in could have influenced the way in which I phrased questions and affected the scores on the APEND or DKQ questionnaire. I was aware of the potential for this effect and tried to discuss the questions in as neutral terms as possible with all participants. I also deferred discussions about dementia to after completion of the questionnaires if participants asked me questions about it. However, it is not possible to completely rule out the effects of bias in this study.

11.8.7 Social acceptability bias

The initial visit was always conducted in person and I was aware that as a health professional asking people their attitudes to help-seeking from health professionals may introduce social acceptability bias. It is also possible that people in the intervention group were more prone to this bias because they were aware they had received the intervention and therefore might be expected to feel more positively about help-seeking for memory problems and this could be why people who viewed the intervention had higher scores on the APEND Behavioural Intention subscale. I was aware of this potential for bias so tried to be as neutral as possible if asked to explain questions, to minimise bias. Participants did tend to score help-seeking for dementia more favourably than might be expected but this was not exclusively the case so I can only assume that their answers were reflective of what they truly thought and not what they thought I would want to hear.

11.8.8 Lack of baseline assessment

This study was funded by a fellowship and did not include funding for a research assistant. For greater practicality, the study design involved seeing participants after they had received the intervention and then three months after the initial contact in order to consider feasibility and acceptability with the assumption that they would be the same as each other at baseline because of randomisation. This meant the study lacked a baseline score on the APEND and DKQ and scores could not be compared before and after receiving the intervention. The scores on the questionnaires were not the main outcomes of

interest and so measuring change on them was less important. The assumption was that randomisation would ensure equal distribution of relevant characteristics between groups so that any observed differences would come from the intervention. As discussed in the previous section, randomisation did not work in this way and scores on the questionnaires were higher in the control group at both time points. However, this means that the higher scores in the intervention group who had viewed the intervention may be more promising as it goes against the naturally observed differences. As I did not measure scores on the questionnaires before receiving the intervention, I may have underestimated, or, less likely overestimated, the effect of the intervention. Measuring scores on the questionnaires at two time points was intended to give information about whether any differences in the two groups persisted beyond any initial effect but the delay between sending the intervention and seeing participants could again have resulted in an underestimation of effects of the intervention.

11.8.9 Variable time to first and follow-up visits

Another potential problem with the assessments was that they occurred at a variable time after participants were sent the intervention. I sent participants the intervention as soon as they had verbally consented to take part in the study and then made an appointment to see them and obtain written consent and complete the questionnaire. Variability in participants' availability meant that some people received the intervention a shorter time period than others before completing the questionnaire. This should not, however, make a

significant difference to results as ideally any intervention aimed at altering attitudes to help-seeking should be able to maintain an effect over a few weeks.

11.9 Further work

11.9.1 Full-scale randomised controlled trial

There were significant difficulties in recruiting to the study through primary care. Only 50% of GP practices consented to enter the trial. Out of the 1462 potential participants, 7% responded, of which 76% consented to be in the trial. It is unclear what strategies I could use to enhance recruitment, as I already used a financial incentive and GP letters to engage potential participants.

The results of this pilot study are promising in terms of the possible effect of the intervention in those who viewed it. However, less than half of people who were sent the intervention actually looked at it. I could modify the letter sent out with the intervention, for example, by using the NHS stamp on the outside of the envelope, in order to try and increase the percentage of people who viewed the intervention but this would still require a huge amount of investment in terms of time and money. Recruitment in primary care was time consuming and mailing out thousands of letters for a small response rate and low viewing rates was costly.

Pilot randomised controlled trials are often used to calculate numbers needed for a full-scale randomised trial pilot study but do not provide a meaningful effect size estimate for planning subsequent studies due to the imprecision inherent in data from small samples (Leon et al. 2011). I was aware that there

was significant bias within my study, including selection bias, unequal distribution of participant characteristics and the lack of blinding as to group allocation. Calculating a sample size based on results from a biased study would therefore be imprecise. For these reasons, I have not calculated a sample size for the full-scale RCT.

Given the high acceptability and low costs of the intervention, it could be made freely available to people. It would therefore be more efficient and possibly more effective to disseminate the leaflet and DVD via other means to ensure more people saw it and therefore changes in attitude would be more likely.

11.9.2 Dissemination of the intervention in other ways

Possibilities for dissemination would be putting the leaflet in GP surgery waiting areas and showing the DVD while people wait. Some of my participants suggested this to me and said they would welcome such resources. The intervention could be given to GPs to distribute to their South Asian families. Because the intervention is highly acceptable, consent for sending the intervention out could be obtained from the GP practice, rather than individual patients, as has been done previously (Livingston et al. 2017). If the intervention was coming directly from the GP on stationery that their patients are familiar with and with the practice stamp and other NHS identifiers on the envelope, this might make it more likely that people would look at it.

There are approximately 1.5 million South Asians in London and it is estimated that 17% of the British Asian population is over the age of 50 (Office for

National Statistics 2015) which equates to 255,000 South Asians over the age of 50 in London. It would be relatively easy for GPs to mail out the intervention to all South Asians over the age of 50 registered with them and even if only 41% of these people looked at the intervention, this would still be reaching a significant percentage of the population.

Another possibility would be to disseminate the information through community centres and organisations. This may not achieve as high coverage of the South Asian population though, as only a subset of people with be members of such organisations.

11.9.2.1 Adaptations

Apart from Bengali, Urdu, Punjabi and Gujarati are commonly spoken South Asian languages in the UK so it would be desirable to translate the intervention into these languages at least to make them more accessible.

11.9.2.2 Involving GPs

It may be that viewing the intervention might encourage people from the South Asian community to seek help earlier for memory problems but as seen from previous studies, this does not always translate to more referrals by GPs to specialist services (Livingston et al. 2017). It may be that a joint approach is needed, to empower patients, encourage referrals from GPs and engage with memory services.

11.9.2.3 Use of different outcomes

Future assessment of the impact of the intervention would ideally include measures of actual help-seeking as, although there were some questions about help-seeking in this study, the primary focus was intention to seek help and not help-seeking itself. One possibility would be to deliver the intervention in GP practices and compare the numbers of people seeking help for memory problems in GP practices with the intervention and those without. There would also need to be a consideration of whether those who seek help are then referred on for further assessment and obtain a diagnosis or whether help-seeking is only increased in the ‘worried well’.

12 : Conclusions

Obtaining a diagnosis of dementia early in the illness is likely to be advantageous and not knowing the diagnosis till times of crisis disadvantageous, so it is concerning that people from minority ethnic groups may seek and obtain help later. My systematic review found that education of GPs may increase the number of suspected cases that are referred for specialist assessment but there were no interventions aimed at increasing help-seeking in those developing symptoms. Since then an intervention to encourage help-seeking for memory problems in the general population has increased numbers of patients seeing their GPs but this has not resulted in onward referrals for specialist assessment (Livingston et al. 2017). There have been no interventions specifically targeted at minority ethnic groups. I have found, in an observational study, that dementia diagnosis rates increased after launch of the National Dementia Strategy, indicating that policy-level changes can have an impact on diagnosis rates.

I used qualitative methods to investigate barriers to help-seeking for dementia among the South Asian community and to find ways of encouraging earlier help-seeking and found different barriers to the majority UK community.

The primary aim of this study was to develop and test the feasibility and acceptability of an intervention to improve attitudes to help-seeking among South Asian people. I have used a rigorous and replicable process, based on previous research, best practice guidelines and in collaboration with South

Asian community members and healthcare professionals, to develop the intervention.

This is the first intervention targeted at the South Asian population to encourage earlier help-seeking for dementia. Design of the intervention used an established behaviour change theory, used a behaviour change design framework and aimed to be as accessible as possible. This pilot RCT shows the intervention is acceptable and it is feasible to recruit people through GP practices, disseminate the information and follow people up. I found, however, that recruiting in this way for an RCT was laborious and time-consuming and, given that the intervention was acceptable, another method of dissemination may be preferable.

Exploratory analyses on intention to seek help for dementia are promising but further work is needed in translation of the resources to other languages, finding better methods of dissemination and measuring help-seeking behaviour.

12.1 Wider implications and research impact

This thesis has highlighted the potential impact that policy change can have on diagnosis rates for dementia in the general population but has also highlighted that we do not know how dementia diagnosis rates have varied over time in the South Asian population. I have shown that untargeted educational leaflets do not affect help-seeking for dementia and that cultural

differences in the understanding of dementia and the response to dementia symptoms exist and should be considered when designing healthcare policies and interventions. Finally I have used a replicable method for designing and testing a culturally targeted intervention and shown that it may be possible to bring about changes in attitudes towards help-seeking for dementia by targeting known barriers. These principles can be applied to future healthcare policies and can be used to design and adapt other interventions.

12.2 Future directions

During the course of my PhD I have gained experience in qualitative methodology, systematic reviews, analysis of longitudinal data and conducting a pilot randomised controlled trial. I have addressed the primary outcomes for my own study and have had a chance to explore in greater depth the experiences of people from the South Asian community with regards to dementia and help-seeking. The PhD has also led to collaborations and an expansion of my research interests.

As mentioned above, I am a collaborator on a similar project to devise and test an intervention to encourage help-seeking for dementia in the Black community in Greater London.

I am part of the London Dementia Strategic Clinical Network Working Group on Reducing Dementia Inequalities and plan to use this as a platform to share my intervention widely and disseminate it.

The principles of cultural adaptation that I learned in this trial may be useful to adapt other interventions for use in the South Asian community and I am a co-applicant on a shortlisted grant to adapt The START (Livingston et al. 2013) - an intervention for carers of people with dementia - with Gill Livingston.

The prevalence of dementia in the South Asian population is still far from clear. In order to establish the extent of inequalities relating to dementia diagnosis and management I am analysing data from local memory services and I am also collaborating with Claudia Cooper on a grant to analyse GP electronic data on ethnicity, dementia diagnoses and care.

12.3 Summary

This study showed it is possible to design and test an acceptable and culturally targeted intervention to encourage help-seeking for dementia in South Asian people. Dissemination of this intervention may be better using means other than sending it to individuals, such as using GP waiting rooms or community centres. Further cultural adaptations would be helpful in ensuring it reaches a wider audience.

13 References

Abraham, C. & Michie, S. 2008. A taxonomy of behavior change techniques used in interventions. *Health Psychology*, 27, (3) 379-387

Ahmed S.M. & Lemkau J.P. 2000. Cultural issues in the primary care of South Asians. *Journal of Immigrant Health*, 2, (2) 89-96

Ajzen I. 1985, "From intentions to actions: a theory of planned behavior," *In Action control: from cognition to behavior*, Kuhl J. & Beckmann J., eds., Heidelberg: Springer, pp. 11-39.

Ajzen I. Constructing a theory of planned behavior questionnaire. 2002.
Ref Type: Online Source

Ajzen, I. 1991. The theory of planned behavior. *Organizational behavior and human decision processes*, 50, (2) 179-211

Ajzen, I. 2015. The theory of planned behaviour is alive and well, and not ready to retire: a commentary on Sniehotta, Presseau, and Araujo-Soares. *Health Psychology Review*, 9, (2) 131-137

All-Party Parliamentary Group on Dementia 2010, *A misspent opportunity? Enquiry into the funding of the National Dementia Strategy*.

Altman, D.G. & Bland, J.M. 1999. How to randomise. *BMJ*, 319, (7211) 703-704

Alzheimer's society 2012, *Mapping the dementia gap 2011*.

Alzheimer's society 2013, *Mapping the dementia gap 2012*.

Alzheimer's society 2014, *Dementia UK: Update*.

Arain, M., Campbell, M.J., Cooper, C.L., & Lancaster, G.A. 2010. What is a pilot or feasibility study? A review of current practice and editorial policy. *BMC medical research methodology*, 10, (1) 67

Bamford, C., Lamont, S., Eccles, M., Robinson, L., May, C., & Bond, J. 2004. Disclosing a diagnosis of dementia: a systematic review. *International Journal of Geriatric Psychiatry*, 19, (2) 151-169

Banerjee, S., Willis, R., Matthews, D., Contell, F., Chan, J., & Murray, J. 2007. Improving the quality of care for mild to moderate dementia: an evaluation of the Croydon Memory Service Model. *International Journal of Geriatric Psychiatry*, 22, (8) 782-788

Banerjee, S. & Wittenberg, R. 2009. Clinical and cost effectiveness of services for early diagnosis and intervention in dementia. *International Journal of Geriatric Psychiatry*, 24, (7) 748-754

Bank of England. Inflation calculator. 2013. 21-11-2013.
Ref Type: Online Source

Barnett, J.H., Lewis, L., Blackwell, A.D., & Taylor, M. 2014. Early intervention in Alzheimer's disease: a health economic study of the effects of diagnostic timing. *BMC neurology*, 14, (1) 101

Barter, C. & Renold, E. 1999. The use of vignettes in qualitative research. *Social research update*, 25, (9) 1-6

Barton, C., Miller, B., & Yaffe, K. 2006. Improved evaluation and management of cognitive impairment: results of a comprehensive intervention in long-term care. *Journal of the American Medical Directors Association*, 7, (2) 84-89

Batsch N.L. & Mittelman M.S. 2012, *World Alzheimer Report 2012: overcoming the stigma of dementia.*, Alzheimer's Disease International, London.

Berwald, S., Roche, M., Adelman, S., Mukadam, N., & Livingston, G. 2016. Black African and Caribbean British Communities' Perceptions of Memory Problems: "We Don't Do Dementia.". *PLoS One.*, 11, (4) e0151878 available from: PM:27045999

Bhatnagar, K. & Frank, J. 1997. Psychiatric disorders in elderly from the Indian sub-continent living in Bradford. *International Journal of Geriatric Psychiatry*, 12, (9) 907-912

Bhugra, D. & Hicks, M.H. 2004. Effect of an educational pamphlet on help-seeking attitudes for depression among British South Asian women. *Psychiatric Services*, 55, (7) 827-829

Boise, L., Eckstrom, E., Fagnan, L., King, A., Goubaud, M., Buckley, D.I., & Morris, C. 2010. The rural older adult memory (ROAM) study: a practice-based intervention to improve dementia screening and diagnosis. *Journal of the American Board of Family Medicine: JABFM*, 23, (4) 486-498

Bond, M., Rogers, G., Peters, J., Anderson, R., Hoyle, M., Miners, A., Moxham, T., Davis, S., Thokala, P., Wailoo, A., Jeffreys, M., & Hyde, C. 2012. The effectiveness and cost-effectiveness of donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease (review of Technology Appraisal No. 111): a systematic review and economic model. [Review]. *Health Technology Assessment (Winchester, England)*, 16, (21) 1-470

Borson, S., Scanlan, J., Hummel, J., Gibbs, K., Lessig, M., & Zuhr, E. 2007. Implementing routine cognitive screening of older adults in primary care: process and impact on physician behavior. *Journal of General Internal Medicine*, 22, (6) 811-817

Bower, P., Wilson, S., & Mathers, N. 2007. Short report: how often do UK primary care trials face recruitment delays? *Family Practice*, 24, (6) 601-603

Bowler, J.V., Munoz, D.G., Merskey, H., & Hachinski, V. 1998. Factors affecting the age of onset and rate of progression of Alzheimer's disease. *Journal of Neurology, Neurosurgery & Psychiatry*, 65, (2) 184-190

Braun V. & Clarke V. 2006. Using thematic analysis in psychology. *Qualitative research in psychology*, 3, (2) 77-101

Brodaty, H., Green, A., & Koschera, A. 2003. Meta–analysis of psychosocial interventions for caregivers of people with dementia. *Journal of the American Geriatrics Society*, 51, (5) 657-664

Bunn, F., Goodman, C., Sworn, K., Rait, G., Brayne, C., Robinson, L., McNeilly, E., & Iliffe, S. 2012. Psychosocial factors that shape patient and carer experiences of dementia diagnosis and treatment: a systematic review of qualitative studies. *PLoS Med*, 9, (10) e1001331

Carpenter, B.D., Xiong, C., Porensky, E.K., Lee, M.M., Brown, P.J., Coats, M., Johnson, D., & Morris, J.C. 2008. Reaction to a dementia diagnosis in individuals with Alzheimer's disease and mild cognitive impairment. *Journal of the American Geriatrics Society*, 56, (3) 405-412

Chan, K.Y., Wang, W., Wu, J.J., Liu, L., Theodoratou, E., Car, J., Middleton, L., Russ, T.C., Deary, I.J., Campbell, H., Wang, W., & Rudan, I. 2013. Epidemiology of Alzheimer's disease and other forms of dementia in China, 1990-2010: a systematic review and analysis. *Lancet*, 381, (9882) 2016-2023 available from: PM:23746902

Chan, T., van, V.J., Dhoul, N., & de, L.S. 2010. Using routinely collected data to evaluate a leaflet campaign to increase the presentation of people with memory problems to general practice: a locality based controlled study. *Informatics in Primary Care*, 18, (3) 189-196

Connell, C.M., Boise, L., Stuckey, J.C., Holmes, S.B., & Hudson, M.L. 2004. Attitudes toward the diagnosis and disclosure of dementia among family caregivers and primary care physicians. *The Gerontologist*, 44, (4) 500-507

Cooper C, Tandy R, Balamurali TBS, & Livingston G 2010. A systematic review and metaanalysis of ethnic differences in use of dementia treatment, care, and research. *American Journal of Geriatric Psychiatry*, 18, (3) 193-203

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. 2008. Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ*, 337, a1655

Daker-White, G., Beattie, A.M., Gilliard, J., & Means, R. 2002. Minority ethnic groups in dementia care: a review of service needs, service provision and models of good practice. *Aging & Mental Health*, 6, (2) 101-108

Demyan, A.L. & Anderson, T. 2012. Effects of a brief media intervention on expectations, attitudes, and intentions of mental health help seeking. *Journal of Counseling Psychology*, 59, (2) 222-229

Department of Health 2009, *Living well with dementia: A National Dementia Strategy*, Department of health, London.

Department of Health 2013, *Dementia: a state of the nation report on dementia care and support in England*.

Department of Health 2015, *Prime Minister's challenge on dementia 2020*.

Derksen, E., Vernooij-Dassen, M., Gillissen, F., Olde Rikkert, M., & Scheltens, P. 2006. Impact of diagnostic disclosure in dementia on patients and carers: qualitative case series analysis. *Aging and Mental Health*, 10, (5) 525-531

Dodge, H.H., Buracchio, T.J., Fisher, G.G., Kiyohara, Y., Meguro, K., Tanizaki, Y., & Kaye, J.A. 2012. Trends in the prevalence of dementia in Japan. *Int.J.Alzheimers Dis.*, 2012, 956354 available from: PM:23091769

Donegan, K., Fox, N., Black, N., Livingston, G., Banerjee, S., & Burns, A. Secular trends in patterns of diagnosis and treatment for people with dementia in the UK, 2005-2015. The Lancet Public Health . 2017.
Ref Type: In Press

Downs, M., Turner, S., Bryans, M., Wilcock, J., Keady, J., Levin, E., O'Carroll, R., Howie, K., & Iliffe, S. 2006. Effectiveness of educational interventions in improving detection and management of dementia in primary care: cluster randomised controlled study. *BMJ*, 332, (7543) 692-696

Eldridge, S.M., Lancaster, G.A., Campbell, M.J., Thabane, L., Hopewell, S., Coleman, C.L., & Bond, C.M. 2016. Defining feasibility and pilot studies in preparation for randomised controlled trials: development of a conceptual framework. *PLoS One*, 11, (3) e0150205

Francis, J.J., Eccles, M.P., Johnston, M., Walker, A., Grimshaw, J., Foy, R., Kaner, E.F., Smith, L., & Bonetti, D. 2004. Constructing questionnaires based on the theory of planned behaviour. *A manual for health services researchers*, 2010, 2-12

Gao, S., Ogunniyi, A., Hall, K.S., Baiyewu, O., Unverzagt, F.W., Lane, K.A., Murrell, J.R., Gureje, O., Hake, A.M., & Hendrie, H.C. 2016. Dementia incidence declined in African-Americans but not in Yoruba. *Alzheimers Dement.*, 12, (3) 244-251 available from: PM:26218444

Gardner W., Mulvey E.P., & Shaw E.C. 1995. Regression analysis of counts and rates: Poisson, overdispersed Poisson and negative binomial models. *Psychological Bulletin*, 118, 392-404

Gaugler, J.E., Ascher-Svanum, H., Roth, D.L., Fafowora, T., Siderowf, A., & Beach, T.G. 2013. Characteristics of patients misdiagnosed with AlzheimerΓÇÖs disease and their medication use: an analysis of the NACC-UDS database. *BMC geriatrics*, 13, (1) 137

Gibson, G., Newton, L., Pritchard, G., Finch, T., Brittain, K., & Robinson, L. 2016. The provision of assistive technology products and services for people with dementia in the United Kingdom. *Dementia*, 15, (4) 681-701

Godin, G. & Kok, G. 1996. The theory of planned behavior: a review of its applications to health-related behaviors. *American Journal of Health Promotion*, 11, (2) 87-98

Graham, C., Ballard, C., & Sham, P. 1997. Carers' knowledge of dementia and their expressed concerns. *International Journal of Geriatric Psychiatry.*, 12, (4) 470-473

Gulliver, A., Griffiths, K.M., Christensen, H., & Brewer, J.L. 2012a. A systematic review of help-seeking interventions for depression, anxiety and general psychological distress. *BMC Psychiatry*, 12, (81) 1-12

Gulliver, A., Griffiths, K.M., Christensen, H., Mackinnon, A., Calear, A.L., Parsons, A., Bennett, K., Batterham, P.J., & Stanimirovic, R. 2012b. Internet-based interventions to promote mental health help-seeking in elite athletes: an exploratory randomized controlled trial. *Journal of Medical Internet Research*, 14, (3) e69

Hager, K., Baseman, A.S., Nye, J., Brashear, H.R., Han, J., Sano, M., Davis, B., & Richards, H.M. 2014. Effects of galantamine in a 2–year, randomized, placebo–controlled study in Alzheimers disease. *Neuropsychiatric disease and treatment*, 10, 391-401

Hailstone, J., Mukadam, N., Owen, T., Cooper, C., & Livingston, G. 2016. The development of Attitudes of People from Ethnic Minorities to Help-Seeking for Dementia (APEND): a questionnaire to measure attitudes to help-seeking for dementia in people from South Asian backgrounds in the UK. *International Journal of Geriatric Psychiatry., 2016 Mar 21.*

Health and Social Care Information Centre. HSCIC hospital prescribing figures. 2013a. 6-8-2013a.
Ref Type: Online Source

Health and Social Care Information Centre. NHS iView. 2013b. 6-8-2013b.
Ref Type: Online Source

Health and Social Care Information Centre. NHS prescriptions dispensed in the community. 2013c. 6-8-2013c.
Ref Type: Online Source

Health and Social Care Information Centre. Prescriptions cost analysis. 2013d. 6-8-2013d.
Ref Type: Online Source

Health and Social Care Information Centre. Quality Outcomes Framework (QOF), DEM2 indicator, split by PCT. 2013e. 6-8-2013e.
Ref Type: Online Source

Hinton, L., Franz, C., & Friend, J. 2004. Pathways to dementia diagnosis: evidence for cross-ethnic differences. *Alzheimer Dis.Assoc.Disord.*, 18, (3) 134-144 available from: PM:15494619

Howard, R., McShane, R., Lindesay, J., Ritchie, C., Baldwin, A., Barber, R., Burns, A., Dening, T., Findlay, D., & Holmes, C. 2015. Nursing home placement in the Donepezil and Memantine in Moderate to Severe Alzheimer's Disease (DOMINO-AD) trial: secondary and post-hoc analyses. *The Lancet Neurology*, 14, (12) 1171-1181

Hurt, C.S., Burns, A., Brown, R.G., & Barrowclough, C. 2012. Why don't older adults with subjective memory complaints seek help? *International Journal of Geriatric Psychiatry*, 27, (4) 394-400

Hutchinson J. & Smith A.D. 1996. *Ethnicity* Oxford University Press.

Iliffe, S., Wilcock, J., Drennan V., Goodman C., Griffin, M., Knapp M., Lowery D., Manthorpe J., Rait G., & Warner J. Changing practice in dementia care in the community: developing and testing evidence-based interventions, from timely diagnosis to end of life (EVIDEM). NIHR PGfAR Programme - Project Ref. RP-PG-0606-1247. 2013.
Ref Type: Unpublished Work

Iliffe, S., Wilcock, J., Drennan V., Goodman C., Griffin, M., Knapp M., Lowery D., Manthorpe J., Rait G., & Warner J. Changing practice in dementia care in the community: developing and testing evidence-based interventions, from timely diagnosis to end of life (EVIDEM). NIHR PGfAR Programme - Project Ref. RP-PG-0606-1247. 2015.
Ref Type: Serial (Book,Monograph)

Jacqmin-Gadda, H., Sibillot, S., Proust, C., Moline, J.-M., & Thiebaut, R. 2007. Robustness of the linear mixed model to misspecified error distribution. *Computational Statistics and Data Analysis*, 51, (10) 5142-5154

Johl, N., Patterson, T., & Pearson, L. 2014. What do we know about the attitudes, experiences and needs of Black and minority ethnic carers of people with dementia in the United Kingdom? A systematic review of empirical research findings. *Dementia*, 15, (4) 721-742

Jorm A.F. & Jolley, D. 1998. The incidence of dementia: a meta-analysis. *Neurology*, 51, 728-733

Kalaria, R.N., Maestre, G.E., Arizaga, R., Friedland, R.P., Galasko, D., Hall, K., Luchsinger, J.A., Ogunniyi, A., Perry, E.K., Potocnik, F., Prince, M., Stewart, R., Wimo, A., Zhang, Z.X., Antuono, P., & World Federation of Neurology Dementia Research Group 2008. Alzheimer's disease and vascular dementia in developing countries: prevalence, management, and risk factors. [Review] [220 refs][Erratum appears in Lancet Neurol. 2008 Oct;7(10):867]. *Lancet Neurology*, 7, (9) 812-826

Kelly, M.P. & Barker, M. 2016. Why is changing health-related behaviour so difficult? *Public Health*, 136, 109-116

Kitzinger, J. 1994. The methodology of focus groups: the importance of interaction between research participants. *Sociology of health & illness*, 16, (1) 103-121

Knapp M. & Prince M. 2007, *Dementia UK: The full report*, Alzheimer's Society.

Kreuter, M.W. & Skinner, C.S. 2000. Tailoring: what's in a name? *Health Education Research*, 15, (1) 1-4

Laird, N.M. & Ware, J.H. 1982. Random-effects models for longitudinal data. *Biometrics* 963-974

Langa, K.M., Larson, E.B., & Crimmins, E. 2016. A Comparison of the Prevalence of Dementia in the United States in 2000 and 2012. *JAMA Intern Med*

Lathren, C.R., Sloane, P.D., Hoyle, J.D., Zimmerman, S., & Kaufer, D.I. 2013. Improving dementia diagnosis and management in primary care: a cohort study of the impact of a training and support program on physician competency, practice patterns, and community linkages. *BMC geriatrics*, 13, (1) 134

Lawrence, V., Murray, J., Samsi, K., & Banerjee, S. 2008. Attitudes and support needs of Black Caribbean, south Asian and White British carers of people with dementia in the UK. *Br.J.Psychiatry*, 193, (3) 240-246 available from: PM:18757985

Leon, A.C., Davis, L.L., & Kraemer, H.C. 2011. The role and interpretation of pilot studies in clinical research. *Journal of psychiatric research*, 45, (5) 626-629

Li, R., Cooper, C., Barber, J., Rapaport, P., Griffin, M., & Livingston, G. 2014. Coping strategies as mediators of the effect of the START (strategies for RelaTives) intervention on psychological morbidity for family carers of people with dementia in a randomised controlled trial. *Journal of affective disorders*, 168, 298-305

Lievesley N. 2010, *The future ageing of the ethnic minority population of England and Wales*, The Runnymede Trust, London.

Livingston, G., Baio, G., Sommerlad, A., de Lusignan, S., Poulimenos, S., Morris, S., Rait, G., & Hoe, J. 2017. Effectiveness of an intervention to facilitate prompt referral to memory clinics in the United Kingdom: cluster randomised controlled trial. *PLoS Med*, 14, (3) e1002252

Livingston, G., Barber, J., Rapaport, P., Knapp M., Griffen M., King D., Romeo R., Livingston D., Mummery, C., Walker, Z., Hoe, J., & Cooper C 2014. Long-term clinical and cost-effectiveness of psychological intervention for family carers of people with dementia: a single-blind, randomised, controlled trial. *The Lancet Psychiatry*, 1, (7) 539-548

Livingston, G., Barber, J., Rapaport, P., Knapp, M., Griffin, M., King, D., Livingston, D., Mummery, C., Walker, Z., Hoe, J., Sampson, E.L., & Cooper, C. 2013. Clinical effectiveness of a manual based coping strategy programme (START, STrAtegies for RelaTives) in promoting the mental health of carers of family members with dementia: pragmatic randomised controlled trial. *BMJ*, 347, f6276

Loef, M. & Walach, H. 2013. Midlife obesity and dementia: meta-analysis and adjusted forecast of dementia prevalence in the United States and China. *Obesity.(Silver.Spring)*, 21, (1) E51-E55 available from: PM:23401370

Luce, A., McKeith, I., Swann, A., Daniel, S., & O'Brien, J. 2001. How do memory clinics compare with traditional old age psychiatry services? *International Journal of Geriatric Psychiatry*, 16, (9) 837-845

Malterud, K. 2001. Qualitative research: standards, challenges, and guidelines. *The Lancet*, 358, (9280) 483-488

Matthews, F.E., Stephan, B.C., Robinson, L., Jagger, C., Barnes, L.E., Arthur, A., & Brayne, C. 2016. A two decade dementia incidence comparison from the Cognitive Function and Ageing Studies I and II. *Nat.Commun.*, 7, 11398 available from: PM:27092707

Matthews, F.E., Arthur, A., Barnes, L.E., Bond, J., Jagger, C., Robinson, L., & Brayne, C. 2013. A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function and Ageing Study I and II. *The Lancet* (0) available from: http://www.sciencedirect.com/science/article/pii/S0140673613615706

Mayeda, E.R., Glymour, M.M., Quesenberry, C.P., Johnson, J.K., Perez-Stable, E.K., & Whitmer, R.A. 2017. Survival after dementia diagnosis in five racial/ethnic groups. *Alzheimer's & Dementia*

McCracken, C.F., Boneham, M.A., Copeland, J.R., Williams, K.E., Wilson, K., Scott, A., McKibbin, P., & Cleave, N. 1997. Prevalence of dementia and depression among elderly people in black and ethnic minorities. *British Journal of Psychiatry*, 171, 269-273

McDonald, A.M., Knight, R.C., Campbell, M.K., Entwistle, V.A., Grant, A.M., Cook, J.A., Elbourne, D.R., Francis, D., Garcia, J., & Roberts, I. 2006. What influences recruitment to randomised controlled trials? A review of trials funded by two UK funding agencies. *Trials*, 7, (1) 1

Michie, S. 2008. Designing and implementing behaviour change interventions to improve population health. *Journal of Health Services & Research Policy*, 13, (Suppl 3) 64-69

Michie, S., van Stralen, M.M., & West, R. 2011. The behaviour change wheel: a new method for characterising and designing behaviour change interventions. [Review]. *Implementation Science*, 6, 42

Michie, S.F., West, R., Campbell, R., Brown, J., & Gainforth, H. 2014. *ABC of behaviour change theories* Silverback Publishing.

Moniz-Cook, E., Vernooij-Dassen, M., Woods, B., Orrell, M., & Network, I. Psychosocial interventions in dementia care research: the INTERDEM manifesto. 2011. Taylor & Francis. Ref Type: Generic

Morris, J.C., Edland, S., Clark, C., Galasko, D., Koss, E., Mohs, R., Van Belle, G., Fillenbaum, G., & Heyman, A. 1993. The Consortium to Establish a Registry for Alzheimer's Disease (CERAD) Part IV. Rates of cognitive change in the longitudinal assessment of probable Alzheimer's disease. *Neurology*, 43, (12) 2457

Mukadam N. & Livingston G 2012. Reducing the stigma associated with dementia: approaches and goals. *Aging Health*, 8, (4) 377-386

Mukadam, N., Cooper, C., Basit, B., & Livingston, G. 2011a. Why do ethnic elders present later to UK dementia services? A qualitative study. *International Psychogeriatrics*, 23, (7) 1070-1077

Mukadam, N., Cooper, C., & Livingston, G. 2011b. A systematic review of ethnicity and pathways to care in dementia. [Review]. *International Journal of Geriatric Psychiatry*, 26, (1) 12-20

National Institute for Health and Clinical Excellence. Behaviour change at population, community and individual levels. 2007. 10-10-2012.
Ref Type: Online Source

National Institute for Health Research. NIHR Evaluation, Trials and Studies Glossary. 2015. 1-3-0017.
Ref Type: Online Source

NHS England 2015, *Dementia diagnosis and management: A brief pragmatic resource for general practitioners*.

Noar, S.M., Benac, C.N., & Harris, M.S. 2007. Does tailoring matter? Meta-analytic review of tailored print health behavior change interventions. *Psychological Bulletin*, 133, (4) 673-693

Norton, S., Matthews, F.E., Barnes, D.E., Yaffe, K., & Brayne, C. 2014. Potential for primary prevention of Alzheimer's disease: an analysis of population-based data. *Lancet Neurology*, 13, (8) 788-794

Office for National Statistics 2007, *Population estimates by ethnic group*.

Office for National Statistics 2009, *Report: Decennial Life Tables (2000-02)*, Office for National Statistics, Newport.

Office for National Statistics. Standard Occupational Classification. 2010. 23-1-2015.
Ref Type: Online Source

Office for National Statistics 2012a, *2011 Census - Population and Household Estimates for England and Wales*, Office for National Statistics, Newport.

Office for National Statistics 2012b, *Ethnicity and national identity in England and Wales: 2011*.

Office for National Statistics 2012c, *Health Expectancies at Birth and at Age 65 in the United Kingdom, 2008-2010*, Office for National Statistics, Newport.

Office for National Statistics 2013, *Language in England and Wales, 2011*.

Office for National Statistics. Ethnic group by sex by age. 2015. 23-2-2017.
Ref Type: Online Source

Okamura, H., Ishii, S., Ishii, T., & Eboshida, A. 2013. Prevalence of dementia in Japan: a systematic review. *Dement.Geriatr.Cogn Disord.*, 36, (1-2) 111-118 available from: PM:23860389

Orgeta, V., Leung, P., Yates, L., Kang, S., Hoare, Z., Henderson, C., Whitaker, C., Burns, A., Knapp, M., Leroi, I., Moniz-Cook, E., Peason, S., Simpson, S., Spector, A., Roberts, S., Russell, I.T., deWaal, H., Woods, R.T., & Orrell, M. 2015. Individual cognitive stimulation therapy for dementia: a clinical effectiveness and cost-effectiveness pragmatic, multicentre, randomised controlled trial. *Health Technology Assessment*, 19, (64) 1-108

Orsmond, G.I. & Cohn, E.S. 2015. The Distinctive Features of a Feasibility Study Objectives and Guiding Questions. *OTJR: occupation, participation and health*, 35, (3) 169-177

Parkin, E. & Baker, C. 2016, *Dementia: policy, services and statistics overview*, Commons library.

Perry, M., Melis, R.J., Teerenstra, S., Draskovic, I., van, A.T., van Eijken, M.I., Lucassen, P., & Rikkert, M.G. 2008. An in-home geriatric programme for vulnerable community-dwelling older people improves the detection of dementia in primary care. *International Journal of Geriatric Psychiatry*, 23, (12) 1312-1319

Pinner, G. & Bouman, W.P. 2003. Attitudes of patients with mild dementia and their carers towards disclosure of the diagnosis. *International Psychogeriatrics*, 15, (03) 279-288

Pond, C.D., Mant, A., Kehoe, L., Hewitt, H., & Brodaty, H. 1994. General practitioner diagnosis of depression and dementia in the elderly: can academic detailing make a difference? *Family Practice*, 11, (2) 141-147

Post, S.G. & Whitehouse, P.J. 1995. Fairhill guidelines on ethics of the care of people with Alzheimer's disease: a clinical summary. *Journal of the American Geriatrics Society*, 43, (12) 1423-1429

Prince M., Bryce R., & Ferri C.P. 2011, *World Alzheimer Report 2011: the benefits of early diagnosis and intervention.*, Alzheimer's Disease International, London.

Prince M., Knapp M., Guerchet M., McCrone P., Prina M., Comas-Herrera A., Wittenberg R., Adelaja B., Hu B., King D., & Rehill A.and Salimkumar D. 2014, *Dementia UK: Update*.

Purandare, N., Luthra, V., Swarbrick, C., & Burns, A. 2007. Knowledge of dementia among South Asian (Indian) older people in Manchester, UK. *International Journal of Geriatric Psychiatry*, 22, (8) 777-781

Qiu, C., von, S.E., Backman, L., Winblad, B., & Fratiglioni, L. 2013. Twenty-year changes in dementia occurrence suggest decreasing incidence in central Stockholm, Sweden. *Neurology*, 80, (20) 1888-1894 available from: PM:23596063

Rait, G., Walters, K., Bottomley, C., Petersen, I., Iliffe, S., & Nazareth, I. 2010. Survival of people with clinical diagnosis of dementia in primary care: cohort study. *BMJ*, 341, c3584

Ramakers, I.H. & Verhey, F.R. 2011. Development of memory clinics in the Netherlands: 1998 to 2009. *Aging & Mental Health*, 15, (1) 34-39

Reuser, M., Willekens, F.J., & Bonneux, L. 2011. Higher education delays and shortens cognitive impairment. A multistate life table analysis of the US Health and Retirement Study. *European journal of epidemiology*, 26, (5) 395-403

Ritchie, J., Lewis, J., Nicholls, C.M., & Ormston, R. 2013. *Qualitative research practice: A guide for social science students and researchers* Sage.

Robb, K., Power, E., Kralj-Hans, I., Edwards, R., Vance, M., Atkin, W., & Wardle, J. 2010. Flexible sigmoidoscopy screening for colorectal cancer: uptake in a population-based pilot programme. *Journal of Medical Screening*, 17, (2) 75-78

Robertson R. 2008, *Kicking bad habits: Using information to promote healthy behaviours*, King's Fund, London.

Roche, M., Livingston, G., & Mukadam, N. Pilot randomised controlled trial of an intervention to encourage earlier help-seeking among Black community members in the United Kingdom. 2017.
Ref Type: Personal Communication

Rodriguez, J.J.L., Ferri, C.P., Acosta, D., Guerra, M., Huang, Y., Jacob, K.S., Krishnamoorthy, E.S., Salas, A., Sosa, A.L., & Acosta, I. 2008. Prevalence of dementia in Latin America, India, and China: a population-based cross-sectional survey. *The Lancet*, 372, (9637) 464-474

Rondeau V., Allain H., Bakchine S., Bonet P., Brudon F., Chauplannaz G., Dubois B., Gallarda T., Lepine J., Pasquier F., Pouchain D., Ritchie K., Robert P., Touchon J., Vellas B., Vercelletto M., Verny M., Carcaillon L., Duveau F., Millet V., Tonelli I., Schuck S., & Dartigues J. 2008. General practice-based intervention for suspecting and detecting dementia in France: A cluster based randomized controlled trial. *Dementia*, 7, (4) 433-450

Satizabal, C.L., Beiser, A.S., Chouraki, V., Chene, G., Dufouil, C., & Seshadri, S. 2016. Incidence of Dementia over Three Decades in the Framingham Heart Study. *N.Engl.J.Med.*, 374, (6) 523-532 available from: PM:26863354

Schrijvers, E.M., Verhaaren, B.F., Koudstaal, P.J., Hofman, A., Ikram, M.A., & Breteler, M.M. 2012. Is dementia incidence declining?: Trends in dementia incidence since 1990 in the Rotterdam Study. *Neurology*, 78, (19) 1456-1463 available from: PM:22551732

Seabrooke V. & Milne A. Early intervention in dementia care in an Asian community: lessons from a dementia collaborative project. Quality in Ageing 10[4], 29-36. 2009.
Ref Type: Journal (Full)

Sheikh, S. & Furnham, A. 2000. A cross-cultural study of mental health beliefs and attitudes towards seeking professional help. *Social Psychiatry & Psychiatric Epidemiology*, 35, (7) 326-334

Sniehotta, F. F., Presseau, J., & Araujo-Soares, V. Time to retire the theory of planned behaviour. 2014. Taylor & Francis.
Ref Type: Generic

Snijders T.A.B. & Bosker R.J. 1999. *Multilevel analysis: an introduction to basic and advanced multilevel modelling* London, Sage.

Spector, A., Thorgrimsen, L., Woods, B., Royan, L., Davies, S., Butterworth, M., & Orrell, M. 2003. Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: randomised controlled trial. *British Journal of Psychiatry*, 183, 248-254

Spijker, A., Vernooij-Dassen, M., Vasse, E., Adang, E., Wollersheim, H., Grol, R., & Verhey, F. 2008. Effectiveness of Nonpharmacological Interventions in Delaying the Institutionalization of Patients with Dementia: A Meta-Analysis. *Journal of the American Geriatrics Society*, 56, (6) 1116-1128

Stern, R.G., Mohs, R.C., Bierer, L.M., Silverman, J.M., Schmeidler, J., Davidson, M., & Davis, K.L. 1992. Deterioration on the Blessed test in Alzheimer's disease: longitudinal data and their implications for clinical trials and identification of subtypes. *Psychiatry research*, 42, (2) 101-110

Stevnsborg, L., Jensen-Dahm, C., Nielsen, T.R., Gasse, C., & Waldemar, G. 2016. Inequalities in Access to Treatment and Care for Patients with Dementia and Immigrant Background: A Danish Nationwide Study. *Journal of Alzheimer's Disease*, 54, (2) 505-514

Strack, F. & Deutsch, R. 2004. Reflective and impulsive determinants of social behavior. *Personality & Social Psychology Review*, 8, (3) 220-247

Suh, G.H., Ryu, S.H., Lee, D.W., Han, C., Ju, Y.S., Kee, B.S., Lee, J.N., Bae, J.N., Choi, J.H., & Kim, D.J. 2011. Cholinesterase inhibitors for Alzheimer disease: do they provide more than symptomatic benefits? *The American Journal of Geriatric Psychiatry*, 19, (3) 266-273

Sutherland, S. 1999. *With respect to old age: long term care-rights and responsibilities. The context of long-term care policy*, 1 ed. Stationery Office.

Thai, L.J., Grundman, M., & Klauber, M.R. 1988. Dementia Characteristics of a referral population and factors associated with progression. *Neurology*, 38, (7) 1083

The Bristol BME People Dementia Research Group 2017, *The dementia experiences of people from Caribbean, Chinese and South Asian communities in Bristol*, Alzheimer's Society.

The National Institute for Health and Care Excellence. Dementia guidance and guidelines. 2006. National Institute for Health and Care Excellence. 5-5-2015.
Ref Type: Online Source

The National Institute for Health and Care Excellence 2007, *Behaviour change at population, community and individual levels.*, National Institute for Health and Clinical Excellence, London.

The NHS Information Centre, C. a. M. H. T. 2011, *Establishment of memory services - results of a survey of Primary Care Trusts, final figures 2011*, The Health and Social Care Information Centre.

Tillin, T., Hughes, A.D., Godsland, I.F., Whincup, P., Forouhi, N.G., Welsh, P., Sattar, N., McKeigue, P.M., & Chaturvedi, N. 2013. Insulin resistance and truncal obesity as important determinants of the greater incidence of diabetes in Indian Asians and African Caribbeans compared with Europeans: the Southall And Brent REvisited (SABRE) cohort. *Diabetes Care*, 36, (2) 383-393

Tognoni, G., Alli, C., Avanzini, F., Bettelli, G., Colombo, F., Corso, R., Marchioli, R., & Zussino, A. 1991. Randomised clinical trials in general practice: lessons from a failure. *BMJ*, 303, (6808) 969-971

Tuerk, R. & Sauer, J. 2015. Dementia in a Black and minority ethnic population: characteristics of presentation to an inner London memory service. *BJPsych Bull*, 39, (4) 162-166

United States Census Bureau. Profile America Facts for Features. 2012. 22-2-2017.
Ref Type: Online Source

Vernooij-Dassen, M., Draskovic, I., McCleery, J., & Downs, M. 2011. Cognitive reframing for carers of people with dementia. *Cochrane Database Syst Rev*, 11, (11)

Whitehead, A.L., Sully, B.G., & Campbell, M.J. 2014. Pilot and feasibility studies: is there a difference from each other and from a randomised controlled trial? *Contemporary clinical trials*, 38, (1) 130-133

World Health Organisation 1992, *The International Classification of Diseases Version 10*.

World Health Organization 2012. *Dementia: a public health priority* World Health Organization.

Xie, J., Brayne C., & Matthews, F.E. 2008. Survival times in people with dementia : analysis from population-based cohort study with 14-year follow-up. *BMJ*, 336, (7638) 258-262

Appendix 2: Observational study paper

Open Access Research

BMJ Open

Diagnostic rates and treatment of dementia before and after launch of a national dementia policy: an observational study using English national databases

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ABSTRACT

Objectives: To assess the 2009 National Dementia Strategy's (NDS) impact on dementia diagnosis and treatment.

Setting and participants: Primary care data for England before and after launch of the NDS.

Primary outcome measures: We used nationally available data to estimate the trends over time in rates of dementia diagnoses recorded on the Quality Outcomes Framework (QOF) in Primary Care Trusts (PCT) and antidementia medication prescriptions from 2006/2007 (the first available figures) and the associated increase in cost relative to all other prescriptions. To establish PCT general practitioner (GP) QOF dementia recording validity, we correlated it with medication prescription using the NIC (net ingredient cost).

Results: Regression analysis showed that dementia diagnosis rate was lower prior to launch of the NDS and increased significantly after it was launched. The number of antidementia prescriptions and the cost of antidementia drugs relative to total PCT prescribing costs increased significantly after 2009. GP recording of dementia diagnosis correlated highly with prescription of cholinesterase inhibitors and memantine in the same area ($p<0.001$ each year).

Conclusions: The launch of the NDS was associated with a significant increase in dementia diagnosis rates and prescriptions of antidementia drugs. We cannot establish the causality but this was a change from the prelaunch pattern. Further assessment of any intervention to increase the diagnoses should include an assessment of harm as well as potential benefit.

Strengths and limitations of this study

- To our knowledge, this is the first study to examine the effect of healthcare policy on measurable health outcomes.
- Owing to the nature of the intervention being studied, we could not establish causality.
- The mechanisms of change in diagnostic and prescription rates following the policy launch remain unclear.

INTRODUCTION

The number of people with dementia is rising rapidly worldwide with increased life expectancy[1 2] although the current cohort of older people may have slightly lower rates of dementia than their counterparts 20 years ago.[3] Timely diagnosis of dementia can provide advice, treatment and support which empowers the person with dementia and their family, reduces crises and delays institutionalisation.[4] It also leads to access to treatments, opportunities to take part in research, admission to specialist units when physically ill with a better experience of inpatient care[5] and the ability to plan ahead.[2 4 6] Nonetheless, diagnosis is often late in the illness and the majority of people with dementia are never given a diagnosis,[7] even if they present to their general practitioner (GP) with symptoms.[8] Consequently, early diagnosis is a key aim of current dementia policies in the Western world, including England's National Dementia Strategy[9] but there is dispute about what strategies to use to increase the diagnosis rates, partly centring on the lack of definitive evidence to date on the efficacy of interventions to increase diagnosis[6] or the usefulness of screening.[10]

Barriers to help-seeking for dementia include believing that the symptoms are due to normal ageing, lack of insight of the person with dementia,[11] low levels of knowledge about dementia[12] and a lack of confidence among GPs in discussing this diagnosis.[7 13 14] The National Dementia Strategy (NDS) is the first UK government

initiative to focus on improving dementia care through: raising awareness about the illness; encouraging earlier diagnosis and intervention (primarily by increased access to specialist diagnostic services) and increasing the quality of care that people with dementia receive.[9] It was launched in February 2009 and £150 million of funding was allocated to Primary Care Trusts (PCTs; who at that time commissioned health services for their local areas) to help achieve these objectives. The additional funding was primarily intended to improve diagnosis rates and the quality of dementia care, partly through provision of extra memory clinics. National dementia awareness campaigns were also launched but no specific funding was provided for these.[15]

The NDS is for England, but similar strategies were published for Scotland in June 2010 and Wales in February 2011. Dementia awareness campaigns have been launched in many countries to improve awareness of dementia and reduce stigma, in order to improve detection rates,[7 16] but none of these have been evaluated in terms of their impact on measureable outcomes for people with dementia and their family carers.

Increasing diagnostic rates is theoretically possible through targeting known barriers. Our recent systematic review of interventions to increase either the number of people with diagnoses or timely diagnosis found that increasing the number of memory services was correlated with higher rates of dementia diagnosis[17] and that they diagnosed people earlier in their illness than traditional old-age psychiatry services.[18] In this paper we aim to explore whether there was an increase in diagnosis rates after the NDS compared with the preceding period and whether there was a corresponding increase in the rate of prescription of antidementia medications (cholinesterase inhibitors and memantine).

Objectives

- To assess whether the implementation of the NDS was associated with an increase in the rate of identification of people with dementia.
- To assess whether the NDS was associated with an increase in the treatment of dementia with antidementia medications.
- In addition, we aimed to consider the validity of dementia diagnoses on primary care registers.

METHODS

Data description

We established the following figures in England from national databases and the Alzheimer's Society Mapping the Dementia Gap publications:

- Annual national community-level prescribing data from 2003 to 2012 (calendar year).[19]
- National hospital-level prescribing data from 2007 to 2011 (calendar year).[20]
- Yearly prescribing data of antidementia medications at Primary Care Trust (PCT; an administrative body covering local primary care practices) level for 2008/2009 to 2011/2012 (fiscal year—April to March).[21]
- Number of people diagnosed with dementia on general practitioner (GP) databases by PCT from 2006/2007 to 2011/2012 (these are recorded by GP practice as quality and outcomes framework (QOF) data, fiscal year).[22]
- Estimated true number of people with dementia in each PCT from 2010 to 2012.[23 24]

We divided the number of GP-recorded dementia diagnoses (from QOF registers) by the estimated total number of people with dementia. We used the estimates in the Alzheimer's Society reports of the actual prevalence of dementia in each PCT for 2010–2012. We calculated the prevalence of dementia for preceding years using the same method used by the Alzheimer's Society in their reports.[23 24]

As QOF data rely on GPs to enter dementia diagnosis onto their database, we wished to establish its validity, by comparison with an independent method of estimating the rate of dementia diagnosis, that is, with prescription levels for antidementia drugs calculated by:

- Net ingredient cost (NIC): the cost of the drug before discounts which does not include any dispensing costs or fees.
- Items dispensed: a prescription item refers to a single drug on a prescription so if a prescription form includes three medicines it is counted as three prescription items.[25] The potential disadvantage of relying on this method of calculating costs is that regional or temporal differences in prescribing policy may exist, for example, prescribing for a maximum of 1 month versus prescribing for a maximum of 3 months at a time, which could affect the results significantly.

We used community NIC as hospital NIC data was only available from 2007, was a relatively small figure (approximately 10% of total) and changed over time at around the same rate. We adjusted the NIC for inflation as specified by the Bank of England inflation calculator[26] to enable us to consider whether there were true differences between years. We correlated the NIC and the number of items dispensed to check whether they were similar. The correlation in 2008/2009 between the two was 0.974, in 2009/2010 was 0.968, in 2010/2011 was 0.965 and in 2011/2012 was 0.963 (all p values<0.001), so we concluded that they were very similar. We therefore report only NIC (as it would theoretically be less prone to variation over time and between districts) until 2012 when cholinesterase inhibitors came off-license as follows: Donepezil, February 2012; Galantamine, January 2012; Rivastigmine, July 2012.[27]

We removed Hertfordshire from the dataset in all PCT level data for prescriptions and diagnoses due to West Hertfordshire PCT and East and North Hertfordshire PCT merging into NHS Hertfordshire after 2009/2010.

PCT-level prescribing data rows 'PCT unidentified doctors' and 'PCT unidentified deputising services' were

included when calculating totals but removed for comparison purposes with QOF data at PCT level. These data were never more than 0.06% of the total.

Statistical analysis

Numerical data were summarised using mean and SD or median and range depending on data distribution. We used Spearman's rank correlation to assess the monotonic association between two numerical variables.

Dementia diagnosis rates

We used negative binomial regression (NBR) models to assess the trend in diagnosis rates before and after the NDS, adjusting for cluster at PCT level. The NBR model is appropriate for count data and is similar to the Poisson regression model but is more appropriate in the presence of over-dispersion.[28] The NBR yield estimates of incidence rate ratio (IRR) and 95% CIs, where an IRR value of 1 indicates no impact on diagnosis rates. We used total population at risk as the offset variable in order to adjust for variable population denominators.

Dementia drug prescriptions

We used NBR to assess the trend in the number of dementia drug prescriptions, before and after the NDS, adjusting for cluster at PCT level with the total number of prescriptions as the offset variable.

We used multilevel linear regression to examine the effect of NDS on the relative prescription cost, adjusting for cluster at PCT level.[29] We used residual plots to investigate the assumptions of normality of residuals required by the multilevel models.

Validity of QOF figures

In order to explore whether areas with a calculated low diagnosis rate were explained by lack of recording of dementia diagnoses on the QOF registers, we assessed the relationship between dementia diagnosis rate and NIC costs per person diagnosed with dementia. If there was a bias in reporting then the mean NIC costs per person diagnosed with dementia would be higher than in other areas. We categorised diagnosis data and prescription data into quartiles and then assessed the Spearman's correlation between them.

All models are fitted with year as a fixed effect. Descriptive analyses were carried out in SPSS V.20. All models were fitted in Stata V.12.

RESULTS

Dementia diagnosis numbers and percentages

The number of people with a dementia diagnosis in England appeared to be similar from 2006 to 2008 but increased every year after 2008. This is shown in figure 1. Dementia diagnosis percentages are available online as a data supplement.

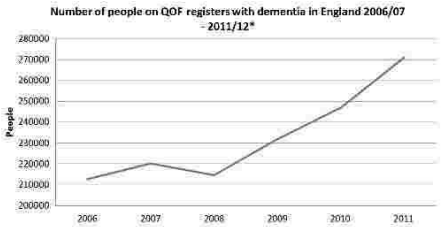

Figure 1 English National diagnosis numbers, 2006/2007 to 2011/2012. *y Axis begins at 200 000 as this was the baseline for numbers on the quality outcomes framework.

Dementia diagnosis rates

Table 1 shows the median number of recorded dementia diagnoses per PCT, the mean proportion of dementia diagnosed per PCT and change in the mean number diagnosed per PCT compared with the previous year, from 2006 to 2012.

Regression analysis showed that dementia diagnosis rates were lower in 2006–2008 compared with 2009, as shown in table 2. The dementia diagnosis rate increased by an estimated 4% in 2010 (IRR 1.04, 95% CI 1.03 to 1.05) and 12% in 2011 (IRR 1.12, 95% CI 1.11 to 1.13) compared with 2009.

Validity of QOF dementia diagnosis data

Dementia diagnosis rates were highly correlated with the prescribing data (see table 3). We divided PCTs into quartiles based on their dementia diagnosis rates and correlated these with the NIC (see table 4). PCTs in the quartile with the lowest diagnosis rates had lower correlations with the NIC than those with the higher diagnosis rates but this was not explained by higher prescribing costs per person diagnosed.

Antidementia drug prescriptions

The rate of prescriptions of antidementia drugs has increased dramatically since 2010 (see figure 2). There was a down-tick in 2012 in cost (see figure 3) although not in the number of prescriptions.

Regression analysis showed that the number of antidementia drug prescriptions increased significantly after 2009. The cost of antidementia drugs relative to total PCT prescriptions costs also increased significantly after 2009. All of these results are shown in table 2.

DISCUSSION

Overall, these results indicate that launch of the NDS is temporally linked to an increase in the diagnosis rates and in prescriptions of antidementia medications in England. We found that the mean number of dementia diagnoses per PCT per year (as reflected in GP recording of the diagnosis on their QOF register) and dementia diagnosis rate increased from the year the NDS was

Table 1 Numbers and percentages of people diagnosed with dementia per Primary Care Trusts (PCT per year)

Year	2006/2007	2007/2008	2008/2009	2009/2010	2010/2011	2011/2012
Median number (range) diagnosed with dementia per PCT	1088 (319–6763	1141.5 (313–7109)	1114 (310–7047)	1186.5 (353–7527)	1286.5 (399–7765)	1419 (448–8058)
Mean dementia diagnosis percentage (SD) per PCT	36.54 (5.6)	37.10 (5.8)	35.85 (5.8)	38.27 (6.1)	40.32 (6.4)	42.29 (6.8)
Mean increase in numbers diagnosed with dementia per PCT (SD) compared to previous year	N/A	48.7 (58.6)	−37.5 (55.8)	111.6 (100.1)	99.2 (75.1)	158.5 (107.7)

launched. Prior to this, there was no clear increase in the number of diagnoses since records began in 2006/2007; therefore, the change does not seem to be just a continuation of a trend that was already occurring or established.

National spending on antidementia medication has also been increasing over time. There was a significant increase in the mean NIC every consecutive fiscal year since 2008/2009 with the decrease in 2012 probably due to the lapsing of patents of cholinesterase inhibitors in England, as prescription numbers continued to increase. We found a larger increase in items prescribed in 2010, the year after the NDS was launched and following the National Institute for Health and Care Excellence (NICE) guideline amendment in August 2009 to allow prescription of cholinesterase inhibitors for mild dementia. The costs of antidementia medications as a proportion of overall spending in PCTs also significantly increased following the launch of the NDS.

The mechanism of this change in diagnostic rates and prescriptions is unclear. The NDS involved provision of additional funding to PCTs. A government review of how this was spent found that less than half of PCTs responded to the survey, of which two-thirds were unable to say where they had allocated the money. Those who could comment on spending mostly prioritised funding memory services and early diagnosis.[30] It is unlikely that those who were unable to say where it was spent used it for dementia and thus it appears that most of the funding was not used for the intended purpose. Therefore, increased spending seems unlikely to be the sole mechanism of change. It is, however, clearly essential to fund services in line with growing demand and ideally this funding should be ringfenced.[31]

The other two elements of the NDS were national dementia awareness campaigns and addressing the quality of dementia care partly through the establishment of memory clinics. A memory clinic survey with an 80% response rate found that the number of people using memory services in each PCT was 1.5 times higher in 2010/2011 than in 2008/2009.[32] In England, consistent with the NICE guidelines, most of the GPs do not diagnose dementia and initiate medication. An increase in diagnosis rates therefore indicates an increase in specialists' diagnoses, probably in memory clinics as they are now the assessment and diagnosis route in most services for people with suspected dementia. This accords with previous reports of an increase in numbers diagnosed with dementia with the establishment of memory clinics.[17 33] Nationally and internationally, relabelling mental health services as 'memory clinics' may also reduce the barrier to diagnosis caused by the stigma of attending mental health services.[34]

It may also be that GPs' and the public's opinion about obtaining a dementia diagnosis has changed with the national awareness campaigns, meaning GPs are more willing to suggest the possibility of the diagnosis and refer patients who are more willing to have further

Table 2 Results of regression analyses for dementia diagnosis and antidementia drug prescriptions

Years	Dementia diagnosis Estimate* (95% CI)	p Value <0.001	Numbers of antidementia drug prescriptions Estimate† (95% CI)	p Value <0.001	Cost of antidementia drugs compared with overall spending Estimate‡ (95% CI)	p Value <0.001
2006	0.96 (0.53 to 0.97)		No data available		No data available	
2007	0.98 (0.97 to 0.98)		No data available		No data available	
2008	0.94 (0.93 to 0.95)		0.88 (0.84 to 0.92)		−0.95 (−1.13 to −0.68)	
2009	Reference year					
2010	1.04 (1.03 to 1.05)		1.11 (1.06 to 1.16)		0.54 (0.27 to 0.81)	
2011	1.12 (1.11 to 1.13)		1.24 (1.19 to 1.29)		2.26 (1.99 to 2.53)	

*Estimates represent incidence rate ratio of dementia diagnosis relative to year 2009 obtained from negative binomial regression, offset against population at risk.
†Estimates represent incidence rate ratio of number of antidementia drug prescriptions relative to year 2009 obtained from negative binomial regression, offset against total number of prescriptions.
‡Estimates represent the mean difference in relative cost of dementia drug obtained by multilevel linear regression compared with 2009.

Table 3 Spearman's rank correlation between numbers of people with dementia diagnoses on PCT quality outcome framework register with PCT level prescription data

Years	Correlation of dementia diagnosis against items dispensed	p Value	Correlation of dementia diagnosis against NIC	p Value
2008/2009	0.58	<0.001	0.61	<0.001
2009/2010	0.57	<0.001	0.61	<0.001
2010/2011	0.57	<0.001	0.62	<0.001
2011/2012	0.56	<0.001	0.61	<0.001

NIC, net ingredient cost; PCT, primary care trust.

assessment, but we were unable to find evidence about opinion stability or change.

Strengths and limitations

To our knowledge, this is the first study to test the effect of government policy on measureable outcomes in dementia. This is an area that deserves further study to ensure the best use of resources in managing dementia and other illnesses.

The QOF provides a financial incentive for GP practices to create and maintain a register of patients with dementia. It is a voluntary reward scheme and there has been some debate about whether it provides an accurate estimate of numbers diagnosed with dementia. We tested its validity and found the QOF data to be highly correlated with prescriptions for antidementia medication, indicating that it is a valid measure of the number of people diagnosed with dementia. There is still a

Table 4 Spearman's rank correlation between dementia diagnosis rates divided into quartiles and prescription costs

Years	Quartile (lowest to highest diagnosis rates)	Number of PCTs* in each group	Mean NIC (SD) per person on dementia register	Correlation between NIC and diagnosis rate	p Value
2009–2010	1st	37	303.4 (177.3)	0.533	0.001
	2nd	38	357.0 (131.5)	0.571	<0.001
	3rd	38	317.0 (166.5)	0.655	<0.001
	4th	37	333.8 (136.2)	0.684	<0.001
2010–2011	1st	37	329.5 (163.6)	0.497	0.002
	2nd	38	328.9 (176.5)	0.604	<0.001
	3rd	38	302.0 (164.6)	0.644	<0.001
	4th	37	358.5 (127.1)	0.764	<0.001
2011–2012	1st	37	331.4 (185.8)	0.384	0.019
	2nd	38	360.4 (167.4)	0.742	<0.001
	3rd	38	337.3 (177.3)	0.548	<0.001
	4th	37	379.3 (136.4)	0.717	<0.001

*NIC, net ingredient cost; PCT, primary care trust.

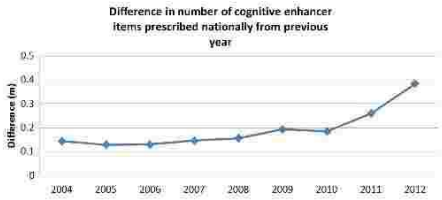

Figure 2 Rate of increase in cognitive enhancer prescriptions over time.

significant amount of variance in prescription which is unexplained by diagnosis rate. However, areas which had low diagnosis rates did not have higher prescription rates per person diagnosed with dementia, indicating that there is not a systematic omission of people with dementia from the QOF register in these areas. Although antidementia drugs are recommended in the UK across all the dementia severity ranges and there is no reason to think that the proportion of people with Alzheimer's dementia varies across areas, we do not know whether some practitioners prescribe in different ways. However, our analysis finds no systematic pattern in the PCTs with low dementia diagnosis percentages and therefore suggests that the low rates are not accounted for only by a failure to record diagnosis.

Owing to the nature of the intervention being studied, we could only establish associations and temporal links between the launch of the NDS and outcomes. It may be that there is another explanation for the changes, including a change in peoples' perceptions about dementia. This could account for the launch of the NDS and the change in diagnosis and prescription rates. Also, the NDS is a policy change with a wide remit and regional variation in its application. It is therefore difficult to say with any certainty which aspect of the NDS may account for the changes in outcomes we have seen. Finally, all our data were retrospective and not specifically collected with the aim of assessing the impact of the NDS, therefore systematic error cannot be ruled out.

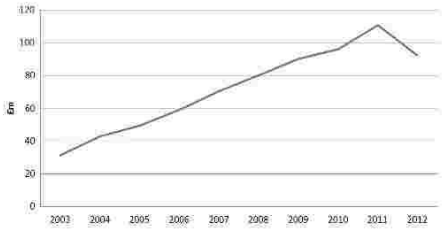

Figure 3 National community net ingredient cost 2003–2012.

Although we did not have any data on the timeliness of the dementia diagnoses being made, if the increase in dementia diagnosis is due to more diagnoses being made in memory services, these diagnoses are likely to be more timely.[18]

Policy and research implications

More than half of people with dementia are still not diagnosed and others are diagnosed late in the illness and therefore do not have the benefits of timely diagnosis described above. If more diagnoses for dementia are made in a timely manner, this should improve individual experience of the illness and have positive implications for health and social care costs. Further effective interventions to increase the number of timely dementia diagnoses are still needed and these interventions should consider harm in terms of anxiety increase in the 'worried well' as well as benefit and cost. As more antidementia drugs come off-license in the UK, costs associated with earlier diagnosis of dementia could fall despite an increase in the number of prescriptions, which could be an important factor in assessing the costs and benefits of future interventions.

Our results suggest that government policy has a significant effect on the number of people diagnosed with dementia and prescription of antidementia drugs but this is unlikely to be due only to additional funding. In particular, more people have accessed the rebadged memory services than mental health services and it may be important to consider the publics' perception of services as well as their funding and operation.

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REFERENCES

1. Luengo-Fernandez R, Leal J, Gray A. *Dementia 2010. The economic burden of dementia and associated research funding in the United Kingdom*. Cambridge: Alzheimer's Research Trust 35, 2010.
2. Ferri CP, Prince M, Brayne C, *et al*. Global prevalence of dementia: a Delphi consensus study. *Lancet* 2005;366:2112–17.
3. Matthews FE, Arthur A, Barnes LE, *et al*. A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function and Ageing Study I and II. *Lancet* 2013;382:1405–12.

4. Prince M, Bryce R, Ferri CP. *World Alzheimer Report 2011: the benefits of early diagnosis and intervention*. London: Alzheimer's Disease International, 2011.
5. Goldberg SE, Bradshaw LE, Kearney FC, *et al*. Care in specialist medical and mental health unit compared with standard care for older people with cognitive impairment admitted to general hospital: randomised controlled trial (NIHR TEAM trial). *BMJ* 2013;347:f4132.
6. Burns A. The benefits of early diagnosis of dementia. *BMJ* 2012;344:e3556.
7. Prince M, Bryce R, Ferri C. *The benefits of early diagnosis and intervention*. Alzheimer's Disease International World Alzheimer Report 2011. 2011.
8. Olafsdottir M, Foldevi M, Marcusson J. Dementia in primary care: why the low detection rate? *Scand J Prim Health Care* 2001;19:194–8.
9. Department of Health. *Living well with dementia: a national dementia strategy*. London: Department of Health, 2009.
10. Brayne C, Davis D. Making Alzheimer's and dementia research fit for populations. *Lancet* 2012;380:1441–3.
11. Livingston G, Leavey G, Manela M, *et al*. Making decisions for people with dementia who lack capacity: qualitative study of family carers in UK. *BMJ* 2010;341:c4184.
12. All-Party Parliamentary Group on Dementia. Unlocking diagnosis: All-Party Parliamentary Group report 2012. 2012.
13. National Audit Office. *Improving services and support for people with dementia*. London: The Stationery Office, 2007.
14. National Audit Office. Improving dementia services in England—an interim report. 14 Jan 2010.
15. House of Commons All-Party Parliamentary Group on Dementia. A misspent opportunity? Inquiry into the funding of the National Dementia Strategy. 2010.
16. Batsch NL, Mittelman MS. *World Alzheimer Report 2012: overcoming the stigma of dementia*. London: Alzheimer's Disease International, 2012.
17. Ramakers IH, Verhey FR. Development of memory clinics in the Netherlands: 1998 to 2009. *Aging Mental Health* 2011;15:34–9.
18. Luce A, McKeith I, Swann A, *et al*. How do memory clinics compare with traditional old age psychiatry services? *Int J Geriatr Psychiatry* 2001;16:837–45.
19. NHS prescriptions dispensed in the community. 2013. 6 Aug 2013.
20. HSCIC hospital prescribing figures. 2013. 6 Aug 2013.
21. NHS iView. 2013. 6 Aug 2013.
22. Quality Outcomes Framework (QOF), DEM2 indicator, split by PCT. 2013. 6 Aug 2013.
23. Alzheimer's society. Mapping the dementia gap 2011. 21 Feb 2012.
24. Alzheimer's society. Mapping the dementia gap 2012. 2013.
25. Prescriptions cost analysis. 2013. 6 Aug 2013.
26. Bank of England. Inflation calculator. 2013. 21 Nov 2013.
27. Cholinesterase inhibitors lapse of licenses in UK. 2013. 21 Aug 2013.
28. Gardner W, Mulvey EP, Shaw EC. Regression analysis of counts and rates: poisson, overdispersed Poisson and negative binomial models. *Psychol Bull* 1995;118:392–404.
29. Snijders TAB, Bosker RJ. *Multilevel analysis: an introduction to basic and advanced multilevel modelling*. London: Sage, 1999.
30. All-Party Parliamentary Group on Dementia. A misspent opportunity? Inquiry into the funding of the National Dementia Strategy. 2010.
31. Hawkes N. Dementia experts are optimistic despite decline in hope for effective drugs. *BMJ* 2013;347:f4265.
32. The NHS Information Centre CaMHT. *Establishment of memory services—results of a survey of Primary Care Trusts, final figures 2011*. 2011. The Health and Social Care Information Centre.
33. Banerjee S, Willis R, Matthews D, *et al*. Improving the quality of care for mild to moderate dementia: an evaluation of the Croydon Memory Service Model. *Int J Geriatr Psychiatry* 2007;22:782–8.
34. Mukadam N, Livingston G. Reducing the stigma associated with dementia: approaches and goals. *Aging Health* 2012;8:377–86.

BMJ Open

Diagnostic rates and treatment of dementia before and after launch of a national dementia policy: an observational study using English national databases

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Appendix 3: Qualitative study paper

Open Access Research

BMJ Open

What would encourage help-seeking for memory problems among UK-based South Asians? A qualitative study

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ABSTRACT

Objectives: People from Minority Ethnic groups tend to present late to dementia services, often in crisis. Culture-specific barriers to help-seeking seem to underlie this. We sought to determine these barriers to timely help-seeking for dementia among people from South Asian backgrounds and what the features of an intervention to overcome them would be.

Study design: Qualitative study to delineate barriers to and facilitators of help-seeking for South Asian adults with dementia through focus groups and individual interviews.

Setting: Community settings in and around Greater London.

Participants: To achieve a maximum variation sample, we purposively recruited 53 English or Bengali speaking South Asian adults without a known diagnosis of dementia through community centres and snowballing.

Results: Participants ranged in age from 18 to 83 years, were mostly female and were 60% Bangladeshi. We recruited people from different religions and occupational backgrounds and included those with experience of caring for someone with dementia as well as those without this experience. Participants identified four main barriers to timely diagnosis: barriers to help-seeking for memory problems; the threshold for seeking help for memory problems; ways to overcome barriers to help-seeking; what features an educational resource should have.

Conclusions: We have identified the features of an intervention with the potential to improve timely dementia diagnosis in South Asians. The next steps are to devise and test such an intervention.

Strengths and limitations of this study

- We purposively recruited a relatively large sample of South Asian people, giving a maximum variation sample.
- We specifically focused on exploring how to create an intervention to encourage more help-seeking within this ethnic group, which has not been done before.
- Our findings cannot be extrapolated to other underserved groups.

BACKGROUND

It is estimated that there are 850 000 people living with dementia in the UK, and the number of people affected is expected to increase to over one million by 2025.[1] Black and Minority Ethnic (BME) people account for 15% of the English population and 39% of the London population.[2] The largest minority group are of South Asian origin accounting for around 7% of the population in England and Wales.[3] The BME population in the UK and other Western countries is younger than the majority population and tends to have a higher proportion of younger onset dementia,[4 5] so the overall burden of dementia is substantial.

People from BME backgrounds underuse services for dementia in the UK, USA and Australia.[6–8] This inequality of service use is thought to lead to poorer dementia outcomes among BME groups and has led to UK policy of ensuring that services are culturally targeted and appropriate and suggesting creating special memory services for BME groups.[5] There is debate about the benefits of earlier diagnosis of dementia, given the lack of curative treatments,[9] and routine screening is unlikely to be of benefit,[10] but earlier diagnosis enables people to make an informed choice about using services and future care, reduces family carer stress and delays institutionalisation. Equal access to dementia services for all ethnic groups is important to ensure these potential health benefits. In the UK, as in other Western countries, early diagnosis of dementia is a national priority.[11]

We reported in a systematic review that barriers to accessing dementia services described in a broad range of BME groups include: attributing the symptoms to normal ageing or other physical, spiritual or psychological causes; denial that there was a problem or normalisation of symptoms; concerns about

stigma related to dementia; perceived ethical imperative to care for one's own family members without accessing help; negative experiences of the healthcare service and feeling there was nothing that could be done for dementia. The only facilitator to help-seeking found was knowledge about dementia.[12] In order to reduce healthcare inequalities, it is important that diverse needs are identified of differing BME groups.[13] Only two of the studies reviewed directly compared help-seeking for dementia in different ethnic groups.

Our previous small study comparing BME groups with the white UK-born population found that certain barriers to help-seeking seemed specific to BME groups, such as different beliefs about the aetiology of symptoms, concerns about stigma and the perceived benefit of looking after your own family until you could no longer cope. Diagnosis alone was also less valued among BME carers than their white UK counterparts.[14] A systematic review specifically focused on dementia and mental illness in people of South Asian origin also found stigma, lack of knowledge about services and culturally preferred coping strategies to be significant barriers to help-seeking.[15]

Thus, barriers to help-seeking for dementia are culturally specific and encouraging help-seeking in BME groups should take these particular concerns into account. Simply providing information about an illness is not sufficient to change health-related behaviour,[16] so we sought to explore what factors would encourage help-seeking among UK-based South Asians.

AIMS

We aimed to explore, in a larger population, South Asian peoples' interpretation of cognitive symptoms and the reluctance behind seeking medical help for these symptoms. We also wanted to explore for the first time what might encourage earlier help-seeking in order to devise an intervention to encourage timely diagnosis.

METHODS

Participants

We defined South Asian as being anyone who identified themselves as having South Asian identity or heritage by links to any South Asian country, primarily India, Pakistan, Bangladesh, Nepal and Sri Lanka. We purposively recruited participants from South Asian community centres and then through snowballing from those contacts and researchers' personal or professional contacts, in order to gain a maximum variation sample and therefore range of opinions; aiming for participants from either gender, a range of marital status, ages, educational background and occupations; people born in the UK and a variety of South Asian countries, and from differing religions. We recruited participants who wished to be in a single-sex only group and those who were comfortable in a mixed sex group and included participants with and without experience of caring for or interacting with people with dementia.

Procedures

All participants provided written consent after reading a participant information sheet and having the opportunity to ask questions. This was done by trained researchers using the principles of the Mental Capacity Act (http://www.legislation.gov.uk/ukpga/2005/9/contents). We conducted focus groups in English or Bengali with an interpreter as needed. Participants were included if they spoke other South Asian languages but could participate in English, but Bengali speakers did not need to be able to speak English. Bengali was chosen as it is one of the most commonly spoken South Asian languages in the UK.[17]

We organised focus groups so they were comprised of people with shared background, for example, attending the same community centre as from the same country of origin, as homogeneity within the group can facilitate more detailed and free flowing consideration of topics and also to allow comparison between groups.[18 19] They were also used to allow group processes to enable participants to explore and clarify their views in ways that may not have been possible using individual interviews.[19] We conducted individual interviews with some participants (eg, a family carer) to explore their experiences in more detail and in a more private setting,[20] and in some cases these were conducted if there were only one or two participants at a centre. We collected demographic information for all participants. Those who were willing and able also answered some written questions about dementia aetiology, attitude to help-seeking for dementia and their own experiences in caring for someone with dementia. Interviewees were given £20 in tokens to thank them for their time.

The interview began with reading out a case vignette describing a South Asian woman with significant memory problems. This was developed in order to describe a person with significant memory problems justifying further investigation, and to ensure content validity we modified it after consultation with memory clinic doctors. Participants were asked what they thought her symptoms were due to and how she should deal with them. Where interpreters were used, they translated the vignette verbatim and spoke it aloud, then translated all facilitator comments and questions as they were issued. Discussion about barriers to help-seeking and how to encourage help-seeking for these kinds of problems was then encouraged using prompts based on previously identified barriers to help-seeking. The interview guide was continually modified according to emerging concepts from focus groups and interviews. Recruitment continued until theoretical saturation was achieved, that is, no new themes were emerging from the data.[21]

Data analysis

Focus groups and individual interviews were audiotaped and transcribed verbatim. Transcripts of individual interviews were sent to participants for validation and comment. Two researchers (NM and AW) analysed the transcripts independently using interpretative

Table 1 Demographic characteristics of participants

Characteristic	Number (percentage)
Mean age (range)	57 (18–83)
Female	31 (58.5)
Ethnicity:	
Bangladeshi	32 (60.4)
Indian	17 (32.1)
Pakistani	2 (3.8)
Other	2 (3.8)
Place of birth	
Bangladesh	31 (58.5)
Africa (various countries)	12 (22.7)
India	6 (11.3)
Pakistan	1 (1.9)
UK	2 (3.8)
Other	1 (1.9)
Mean years in UK (range)	32.0 (4–51)
First language	
Bengali	30 (56.6)
Gujarati	7 (13.2)
English	8 (15.1)
Hindi/Urdu	5 (9.4)
Punjabi	3 (5.7)
Marital status	
Married/living with partner	35 (66.0)
Single	6 (11.3)
Widowed	6 (11.3)
Separated	1 (1.9)
Unknown	5 (9.4)
Religion	
Islam	39 (73.6)
Hinduism	10 (18.9)
Jain	1 (1.9)
Christian	1 (1.9)
Agnostic	1 (1.9)
Unknown	1 (1.9)
Age at leaving full-time education (50 participants)	
No formal education	7 (14.0)
<10	2 (4.0)
10–18	23 (46.0)
19–25	10 (20.0)
>25	6 (12.0)
Unknown	2 (4.0)
Employment:	
Never worked	13 (24.5)
Current/previous occupation	37 (69.8)
Full-time education	3 (5.7)
Unknown	2 (3.7)
SOC Group (2010)	
1. Managers, directors and senior officials	2 (3.7)
2. Professional occupations	8 (15.0)
3. Associate professional and technical occupations	1 (1.9)
4. Administrative and secretarial occupations	6 (11.3)
5. Skilled trades and occupations	6 (11.3)
6. Caring, leisure and other service occupations	3 (5.6)
7. Sales and customer service occupations	2 (3.7)
8. Process, plant and machine operatives	1 (1.9)
9. Elementary occupations	6 (11.3)

SOC, Standard Occupational Classification.

phenomenological analysis.[22] This method was selected because it is best suited to exploring the meaning and significance of experiences of participants in order to gain insight into psychosocial processes. Inductive rather than deductive analysis was applied as there were no specified hypotheses to test and we wished to build a knowledge base up from observations, as is common practice in qualitative research.[23] Emerging themes were discussed and compared across demographic categories. The codes and themes were refined in an iterative process and a final coding scheme was agreed by consensus and with discussion with a third researcher (GL) where needed. We used NVIVO software (QSR International Pty Ltd, V.9, 2010) for our analysis. We have anonymised all quotations, providing non-specific demographic information.

RESULTS

Participants and demographics

We conducted seven focus groups and five individual interviews, with 53 participants in total. The focus groups were held in and around London in a Bengali women's group, a Bengali men's group, an Ismaili community centre, a Hindu cultural group and an Asian women's group. Individual interviews were conducted on University College London premises, in community centres or participants' workplaces. Participants were 58.5% female with a mean age of 57 (range 18–83 years). Most (74%) identified themselves as Muslim and 60% were of Bangladeshi origin. Their demographic characteristics are shown in table 1.

Thirteen of 17 participants who filled in the more detailed questionnaire knew someone with dementia, four of whom had cared for someone who had dementia.

Themes

We looked for patterns in the emergence of themes with regard to whether demographic characteristics or experience with dementia affected people's opinions but found no themes or codes that were exclusive to a particular group or participant characteristic. All themes are therefore presented as relating to the entire sample.

There were four main themes identified. These were: barriers to help-seeking for memory problems; the threshold for seeking help for memory problems; ways

to overcome barriers to help-seeking and what features an educational resource should have. These are discussed below.

Barriers to help-seeking

We divided the barriers discussed into those that occur at the individual level, the societal/community level and the healthcare system level. This grouping was based on the main themes that emerged in group discussions and mapped onto previously described barriers to help-seeking as well as to the theoretical framework described in the Theory of Planned Behaviour which can inform future interventions.[24] These are shown in table 2, along with how frequently they were mentioned in total across all groups and interviews.

Table 2 Barriers to help-seeking for memory problems

	Frequency
Individual	
Lack of acknowledgement that there is a problem due to:	
Fear of institutionalisation	5
Lack of language to describe problems	4
Denial from individual	3
Fear of the diagnosis itself	3
Unwillingness to challenge family hierarchy	2
Wish to maintain position in society	1
Lack of communication	2
Believing that memory problems are due to:	
Old age	9
Social isolation/stressors	9
Psychological cause/mental illness	6
Another physical illness	2
Spiritual cause	1
Feeling that responsibility for getting better lies with:	
The individual themselves	2
The family	1
God	1
Societal	
Perceived stigma of mental illness	10
Stigma of cognitive symptoms	6
Expectation that family should look after their own as long as possible	4
Feeling that dementia is a dangerous illness	2
Healthcare system	
Not knowing what help is available	10
Feeling nothing can be done	4
Language barrier	3
Lack of culturally appropriate help	2
Feeling that the diagnosis itself can never be certain	1
Perception that general practitioners:	
Do not have enough time in consultations	5
Are not useful as a first point of contact	3
Would not take concerns seriously	3
Would say that memory problems are due to old age	2

Individual-level barriers to help-seeking

Memory problems are an inevitable and normal part of ageing

Some participants in each focus group commented that they frequently witnessed memory problems among older members of their families and communities or even among themselves. They regarded these as inevitable and normalised their occurrence, even where their descriptions suggested more serious problems.

> In reality, most of them are having the same problem. At least so many times in a day, my mum, that aunty, they forget things where they put it. Participant number 1, 60–69yo Bangladeshi Muslim woman, no education, focus group

> Something is attributed just to old age and it's going to come and there's nothing you can do about it. P2, 50–59yo Indian Jain woman, tertiary education, interview

Memory problems are not an illness

Another common belief was that social isolation or stressors could cause symptoms.

> The children have grown up, they have their own life, they are not living with parents, and they are feeling lonely, isolated. That's another problem for memory problems. P3, 60–69yo Bangladeshi Muslim woman, minimal education, focus group

The idea that memory problems may be due to spiritual wrongdoing was mentioned.

> It's just that you may not have done something in your previous life, you know, that you're getting some of these problems. P2, 50–59yo Indian Jain woman, tertiary education, interview

One participant expressed the view that it would be up to God to decide if the person has an illness for which help should be sought, although no explanation was given for how this would guide the decision-making process.

> Allah knows if it is an illness or not. P4, 60–69yo Bangladeshi Muslim female, no education, focus group

Individuals or families can make memory problems better

Other participants said that the person or their family could make themselves better.

> So he needs to share his pain or sorrow with a friend who can be assisting, can be supporting him or her. The more you share, you get more breathing space, so you can think better. The dementia we can cure or we build ourself…We need to come out of these things somehow. P5, 50–59yo Bangladeshi Muslim man, tertiary education, focus group

Societal-level barriers to help-seeking

Stigma of diagnosis

Another common theme was the stigma of mental illness and cognitive decline, which is classed as a type of mental illness.

> There is a lot of stigma attached to psychiatric problems and memory falls within that domain. P6, 25–29yo Pakistani agnostic man, post-graduate student, interview

Some participants in each group thought that the stigma of a memory disorder was much worse than that of a chronic medical disorder.

> Most illnesses,…you can be distanced from them and you can deal with them on a practical level. You get diagnosed. You're treated, you do something to make it go away, or live with it, but there is a sense of separation, but with dementia it's more devastating, I think, because it completely takes over the person…it actually takes you away from who you are as a human being, with all these connections that we have. P7, 50–59yo Indian Muslim man, secondary education, interview

Several participants agreed that the stigma in the UK would be less than in their home country.

> The stigma is less here than it would be back home. Back home our families would be sort of outcast, people would avoid going to their homes if they knew there was somebody suffering with this kind of problem. P8, 50–59yo Indian Muslim woman, secondary education, focus group

Participants also linked the stigma of dementia to ideas about dangerousness from neglect.

> People who are…have dementia not only mentally but sometimes become incontinent or they might be a danger to themselves or the society; they might walk away from the house or set the burner on or something. P9, 70–79yo Indian Hindu man, tertiary education, focus group

Good families look after people with dementia themselves

There was a perceived expectation in the community that families would provide care when relatives experience memory problems, without outside help. This was mentioned by a few participants and linked with respect for the affected person and the family hierarchy.

> It is in a way seen as a badge of pride if the family is looking after them whereas there is a lot of stigma in being transferred to mental health services or a care home where they could probably be better looked after. P6, 25–29yo Pakistani agnostic man, post-graduate student, interview

> You couldn't quite discuss that he had memory problems with the wider family or whatever. It's just not done, that would be disrespectful so you know you cope. P2, 52yo Indian Jain woman, tertiary education, interview

One participant commented that families might only feel able to ask for help when the person with memory problems was near the end of their lives.

> You deal with it as best as you can. Maybe they start thinking about receiving help in terms of terminal care. P10, 25–29yo Indian Hindu woman, post-graduate student, interview

Some expressed the view that there was more support available in their home country but this was not accepted by all participants.

> Back home we've got a lot of support in these sort of things. But here, you are stuck in the world by yourself. P5, 50–59yo Bangladeshi Muslim man, tertiary education, focus group

> I don't think so, it's same as here…There are worries everywhere, any country, I believe. P11, 60–69yo Fijian Muslim woman, secondary education, focus group

Healthcare system-level barriers to help-seeking

Lack of knowledge of help available

A commonly mentioned barrier was being unaware of what services were available for cognitive problems.

> People don't know about the services….there's lack of knowledge about the services. P6, 25–29yo Pakistani agnostic man, post-graduate student, interview

Many participants said that they would see their general practitioner (GP) in the first instance about memory problems and expressed the view that health and social care support was very good in the UK. Others had reservations, saying that GP time was limited and GPs would prioritise severe dementia and physical illnesses and dismiss memory problems as being due to old age. Some participants also felt that services needed to have a better understanding of cultural needs and the lack of it led to worse outcomes.

> There are some multifactorial issues as to why Asians don't seek (help) and when they do seek then there isn't a lot of information provided to them so it prevents them from seeking help in the first place and if they do end up in care homes…they aren't looked after as well as they could be. P6, 25–29yo Pakistani agnostic man, post-graduate student, interview

Some participants questioned the meaning of and certainty about a diagnosis.

> Dementia, how certain are you, from after your diagnosis, that it is dementia, and it's not just general forgetfulness? P12, 40–49yo Indian Muslim woman, secondary education, focus group

One participant commented that memory and cognitive problems were not discussed at GP appointments until there was a crisis:

When they go to see the GP, the conversation of tell me what's happening to you, they come out with physical symptoms rather than you know impairment of other kinds…It doesn't come up until you're into crisis. P2, 50–59yo Indian Jain woman, tertiary education, interview

Some participants also mentioned that services may be harmful, feeling afraid that disclosing cognitive symptoms could result in having to leave their own home.

I think some people don't want to tell other people that they're forgetting, they're scared that they would think that they're crazy or if they're living alone, try and get them admitted or something. People are scared of that, you know. P8, 50–59yo Indian Muslim woman, secondary education, focus group.

The threshold for help-seeking

Several participants in each group felt that help should be sought for memory problems as soon as possible. However, while many reported memory problems, only one had sought help.

Some participants said that if symptoms were more frequent or were troubling the individual, then they should ask for help, but this was difficult to quantify.

I think if it's happening more often then it's a cause for concern. P13, 60–69yo Indian Muslim woman, secondary education, focus group

More commonly, people said they would get help if there was a specific event that was severe or risky

If I forget an appointment, or if I forget the timing of an appointment, I'd consider that a minor matter and it wouldn't alarm me. But if I got up and I didn't know what day it was, or what the date was, or if I found myself and didn't know where I was or how I'd got there, then I think it would be a cause for me to be alarmed. P14, 40–49yo Pakistani Muslim woman, secondary education, interview

Participants also said that they would get help for behavioural changes, self-neglect, psychological symptoms like anxiety and any sort of risk, such as fire risk or not remembering if they had taken their medications. However, even the risk of fire was felt not to be significant unless it happened repeatedly.

There would be stronger signs if it's constant. If it's a one-off example you can bypass that. If it's constant, silly things like leaving the gas on, leaving the fire on and then it's getting more and more severe, then leaving the gas on is a very good danger sign for a family…when families need to be alerted, and say "ok, we've got a problem". P15, 30–39yo Bangladeshi Muslim male, tertiary education, focus group

We have people that when they can't take care of themselves but if they have the capacity for the basics like helping with cooking or going for their walks or just taking care of their hygiene and if that is compromised then that is when we seek care but until then it didn't seem like it was necessary as it wasn't that severe. P10, 25–29yo Indian Hindu woman, post-graduate student, interview

Ways to overcome barriers to help-seeking

We asked participants what would encourage them to seek help earlier for cognitive problems.

Normalising help-seeking and breaking down stigma

Several suggested that normalising help-seeking and breaking down the stigma associated with both the symptoms and help-seeking might encourage earlier help-seeking.

The only thing one can do is to tell the particular person that this is nothing uncommon and nothing to be embarrassed about. It happens to all of us and encourage her to seek medical help. P9, 70–79yo Indian Hindu man, tertiary education, focus group

Emphasis that dementia has a physical cause

Some participants mentioned other illness awareness campaigns that they felt had made a significant impact and this highlighted the importance of emphasising the physical rather than mental nature of illness.

If people were introduced to the fact that there is a physical cause…I think if things are explained in a simple and logical manner it'll become more approachable, and understandable, and acceptable. P14, 40–49yo Pakistani Muslim woman, secondary education, interview

Other ways of reducing reluctance to seek help were also used to consider the design of an intervention.

Use a trusted source

Several participants stated that the information should come from a trusted source. Letters from the National Health Service (NHS) and particularly from GPs were felt to have considerable impact and were likely to be read.

You see, because I find if any medical letter comes in, NHS, recently I got a couple of them so I'll read through it whether it concerns me or not, I think one should know. P16, 70–79yo Indian Hindu man, tertiary education, focus group

Target the audience

Some participants felt information should be targeted at South Asian people of all ages, others suggested targeting older people, or those aged 30–40 or specifically women because they would be caring for older relatives. Most agreed that the literature should feature South Asian people:

> Something you can identify with, because usually you know whatever you see, you see a grey haired person and usually a white person so you think well there isn't a connection. P2, 50–59yo Indian Jain woman, tertiary education, interview

Reducing barriers because of language and literacy

Participants suggested that information could be presented in leaflets, a DVD, TV adverts, and videos on GP practice waiting room screens or a combination of these. DVD was the format most frequently endorsed as this would provide more detailed information and use both English and south Asian languages.

Make it clear that the usefulness applies to south Asians by presenting it as a personal story.

> I think the fact that you actually had a description of a person going through the problem caught my interest… That's how I relate to things. P14, 40–49yo Pakistani Muslim woman, secondary education, interview

Important information to include

Participants felt it was important to include information about symptom progression and when to seek help as many people might equate the term dementia with very severe dementia.

> Understanding that you can carry on you know and just understanding the progression because usually people associate dementia with those last stage, you can't recognise anybody, you're incontinent—they only recognise that very end stage they don't recognise from the initial from the very start, that is not people's conception. P2, 50–59yo Indian Jain woman, tertiary education, interview

They felt the benefits of help-seeking should be emphasised.

> While there isn't a cure, I think it's important to realise that there is a lot which can be done for the person during the process. P14, 40–49yo Pakistani Muslim woman, secondary education, interview.

DISCUSSION

This study is the first to consider in more detail the reasons behind the barriers to help-seeking for dementia in UK-based South Asians and what intervention might make a difference. We found as others did that there was stigma but more details of what it was about. Stigma was linked with ideas of "madness", lack of physical aetiology and lack of treatment. Using a case discussion also helped to highlight the dilemma that people with cognitive problems are likely to face—namely, that forgetfulness is a common and normal experience, so it is difficult to differentiate it from significant cognitive impairment, but the study adds to the literature by finding a particularly high threshold for identifying abnormality in this group. In addition, we recruited a wider range of participants than previous studies including those with direct experience of caring for someone with dementia and by seeking potential solutions to the barriers found.

Overall, participants recognised memory problems and felt concerned about them, but there were many barriers to help-seeking, particularly the belief that memory decline was inevitable and not an illness. Reasons behind denial of symptoms, such as wanting to maintain one's position in society or in the family hierarchy and the fear of institutionalisation and the stigma it carries, were interesting and useful. Thus, an intervention could tackle stigma around dementia by reframing it as a possible sign of an underlying physical illness. The study suggests that an intervention should give information about key symptoms which would lead to help-seeking and how that could be beneficial to the person with dementia, as well as the family. Thus, getting help is not seen as relinquishing one" responsibilities, but rather living up to them so that the person with dementia can live as fulfilling a life as possible. Equally, help-seeking could be useful in allaying the fears of those who are not developing dementia.

In this participant group, visual presentation of information was felt to be desirable and people felt more able to relate to a person's story rather than pure clinical information. The source of the information should be trustworthy and the NHS fell into this category. These preferences, while only subtly different to the views of people from other cultural or ethnic groups, represent what this group of South Asian participants felt was important and are the best representation of the views of UK-based South Asians to date; therefore, they are of value in developing a culturally relevant intervention. Some of these barriers to presentation may not be culturally specific, but an intervention which excluded general barriers would clearly not be likely to be effective.

Strengths

This was a relatively large qualitative study with good variation in participant demographic characteristics. Sampling was purposive for characteristics which could have an impact on attitudes to help-seeking for dementia and continued until theoretical saturation was reached. Data analysis was iterative and carried out independently by two researchers to maximise the yield of themes and concepts.

The use of a case vignette and group discussions gave detailed and varied accounts of the help-seeking process. Individual interviews, particularly with professionals with experience of working with people with dementia, provided interesting insights based on personal experiences of working within the South Asian community. Overlap with previously identified barriers to help-seeking in dementia in minority ethnic groups suggests transferability of the findings (12;14).

Limitations

While this relatively large qualitative study gave rich in-depth information about the views of 53 community members, it is not necessarily representative of that whole community, particularly as all participants were from around London and only spoke English or Bengali. South Asians are a large and heterogeneous group, but even in homogeneous groups there will be differences among individuals. There was, however, no apparent influence on opinions expressed according to demographic features, although we considered this in our analysis. Also, as we were asking people about a hypothetical case, it may be that their opinions would change should they face the same situation in reality.

CONCLUSIONS

This study has further explored barriers to help-seeking for dementia in the South Asian community and highlighted ways to overcome these barriers. An intervention should be targeted at known barriers to help-seeking within this community, should use personal narratives and should come from a reliable and trusted source. This might improve help-seeking for dementia in this vulnerable community. We intend to go on to produce, refine and test such an intervention.

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Contributors NM, CC and GL conceived of the study and recruited participants. NM, CC, AW and GL facilitated the focus groups. NM and AW read and coded the transcripts. All authors read and modified the manuscript.

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Competing interests None declared.

Ethics approval Ethical approval for the study was obtained from the National Research Ethics Service committee London—Fulham.

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REFERENCES

1. Prince M, Knapp M, Guerchet M, *et al*. Dementia UK: Update. Alzheimer's Society, 2014.
2. Office for National Statistics. Population estimates by ethnic group. Newport: Office for National Statistics, 2007.
3. Office for National Statistics. *2011 Census—Population and Household Estimates for England and Wales*. Newport: Office for National Statistics, 2012.
4. Adelman S, Blanchard M, Rait G, *et al*. Prevalence of dementia in African-Caribbean compared with UK-born White older people: two-stage cross-sectional study. *Br J Psychiatry* 2011;199:119–25.
5. National Audit Office. *Improving services and support for people with dementia*. London: The Stationery Office, 2007.
6. Bowes A, Wilkinson H. 'We didn't know it would get that bad': South Asian experiences of dementia and the service reponse. *Health Soc Care Community* 2003;11:387–96.
7. House of Commons All-Party Parliamentary Group on Dementia. Dementia does not discriminate. The experiences of black, Asian and minority ethnic communities. All-Party Parliamentary Group on Dementia, 2013.
8. Cooper C, Tandy R, Balamurali TB, *et al*. A systematic review and metaanalysis of ethnic differences in use of dementia treatment, care, and research. *Am J Geriatr Psychiatry* 2010;18:193–203.
9. Burns A. The benefits of early diagnosis of dementia. *BMJ* 2012;344:e3556.
10. Brayne C, Davis D. Making Alzheimer's and dementia research fit for populations. *Lancet* 2012;380:1441–3.
11. Older people and dementia team. Prime Minister's challenge on dementia 2020. Department of Health, 2015.
12. Mukadam N, Cooper C, Livingston G. A systematic review of ethnicity and pathways to care in dementia. *Int J Geriatr Psychiatry* 2011;26:12–20.
13. Moriarty J, Sharif N, Robinson J. *Black and minority ethnic people with dementia and their access to support and services*. London: Social Care Institute for Excellence, 2011.
14. Mukadam N, Cooper C, Basit B, *et al*. Why do ethnic elders present later to UK dementia services? A qualitative study. *Int Psychogeriatr* 2011;23:1070–7.
15. Giebel CM, Zubair M, Jolley D, *et al*. South Asian older adults with memory impairment: improving assessment and access to dementia care. *Int J Geriatr Psychiatry* 2014;30:345–56.
16. Robertson R. *Kicking bad habits: using information to promote healthy behaviours*. London: King's Fund, 2008.
17. Office for National Statistics. Language in England and Wales, 2011. Newport: Office for National Statistics, 2013.
18. Culley L, Hudson N, Rapport F. Using focus groups with minority ethnic communities: researching infertility in British South Asian communities. *Qual Health Res* 2007;17:102–12.
19. Kitzinger J. Qualitative research: introducing focus groups. *BMJ* 1995;311:299–301.
20. Britten J. Qualitative research: qualitative interviews in medical research. *BMJ* 1995;311:251–3.
21. Sandelowski M. Sample size in qualitative research. *Res Nurs Health* 1995;18:179–83.
22. Smith JA. Beyond the divide between cognition and discourse: using interpretative phenomenological analysis in health psychology. *Psychol Health* 1996;11:261–71.
23. Seale C, Gobo G, Gubrium JF, *et al*. *Qualitative research practice*. 2nd edn. Sage, 2014.
24. French SD, Green SE, O'Connor DA, *et al*. Developing theory-informed behaviour change interventions to implement evidence into practice: a systematic approach using the Theoretical Domains Framework. *Implement Sci* 2012;7:38.

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What would encourage help-seeking for memory problems among UK-based South Asians? A qualitative study

Naaheed Mukadam, Amy Waugh, Claudia Cooper and Gill Livingston

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Appendix 4: Participant information sheet - qualitative study

Mental Health Sciences Unit
Charles Bell House
67-73 Riding House Street

London W1P 7NN
Telephone: 0207 679 9467 Fax: 0207 288 3411

Participant information sheet: Improving access to dementia services for minority ethnic elders – focus groups

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

We know that people do better when their memory problems are diagnosed early and they get appropriate help sooner rather than later. We would like to discuss barriers to help-seeking for memory problems with South Asian community members and try to work out what kind of information might encourage people to seek help earlier for memory problems in themselves or someone they care for.

Why have I been invited?

We have approached you to take part in this study because you either belong to a South Asian community centre or know someone who is a member who might have suggested you take part. We wish to speak to people from all different age groups and professions. We have not approached you because we or anyone else has any concerns about your memory.

Do I have to take part?

It is up to you to decide. Please read this information sheet carefully and think about any concerns you may have. If you agree to see us or want to talk on the phone, we can discuss the study in more detail with you and answer any questions or concerns you may have. We will then ask you to sign a consent form to show you have agreed to take part and you will be given a signed copy to keep.

You are free to withdraw from the study at any time, without giving a reason. If you withdraw from the study, you can also request that we not use any of the information you may have already given us. Any stored data that can still be identified as yours will be destroyed if you wish.

What will happen to me / what will I have to do if I take part?

One of the researchers, Dr. Naaheed Mukadam, will contact you in the next week or so to ask if you would like to participate. If you do agree to participate, she will invite you to a discussion group which will be held at a local community site.

Prior to taking part in the discussion group you may be asked to read a short written passage and answer some questions about memory problems. These questionnaires will be anonymous and any information you give us will be confidential. Answering these questions will take around twenty minutes. The discussion group itself will last around an hour. We will ask you some personal details (e.g. age, occupation) as they may be relevant. The group will include people similar to you and we will discuss a person with memory problems, why they might be reluctant to seek help and what kind of information would be helpful in encouraging a person or their family to seek help for memory problems.

The discussion will be tape recorded so we make sure that we do not miss anything that is said. Individuals will not be able to be identified and information will be confidential outside the study.

We will type up the focus group discussion and send it to you. You can make comments and corrections or add things if you wish but you do not have to. We will provide a stamped addressed envelope for you to return your comments to us if you wish to. We will also ask for your comments on our findings from the groups and any materials we develop from them.

We may contact you in the future to ask you to take part in future studies, unless you ask us not to.

Expenses and payments

We can provide reimbursement for travel expenses in attending the focus group and will provide refreshments before the group. In addition, as a small token of our appreciation for your time and your input, we are able to offer you £20 in high street vouchers.

What are the possible disadvantages of taking part?

We do not foresee there being risks associated with the study. We do however appreciate that completing the interview will take up your time.

The discussion group will be held at a local community site, so that it causes the least disruption and inconvenience to you.

There are no right or wrong answers to the questions and you can talk about anything that you feel is relevant. It is possible that some topics discussed may be upsetting if, for example you have had experience of looking after someone with memory problems or if you have noticed memory problems yourself. We will of course bear this in mind and will not require you to discuss anything that you find uncomfortable or sensitive. If at any time during the interview you find a topic sensitive or upsetting you can ask the interviewer to move on to another subject or leave the session altogether. If you feel upset by the interview you can speak to the researcher afterwards or ring the Admiral nurse support helpline (0845 257 9406) which is open from 11am to 8.45pm Tuesdays and Thursdays and 10am to 1pm on Saturdays.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get might help improve the services offered to people with memory problems and the people who care for them.

Will my taking part in the study be kept confidential?

Yes. All interviews and questionnaires are confidential and anonymous so your name will not be disclosed to anyone else and neither will you be identified in any report/publication. If any person in the study tells us that they or someone else is being harmed we will ask their permission to disclose the information to their GP or Consultant Psychiatrist. We respect confidentiality but cannot keep it a secret if anyone is being seriously harmed.

Professional standards of confidentiality will be adhered to and the handling, processing, storage and destruction of data will be conducted in accordance with the Data Protection Act (1998).

Some study documents may also be looked at by authorised representatives from University College London (UCL) Research & Development Unit to check that the study is being carried out correctly. Professional standards of confidentiality will be followed by the authorised representatives.

The information you provide will only be used for the purposes for this research study and not for any other purpose.

Involvement of the General Practitioner/Family doctor (GP)

We will not need to inform your GP of your participation in this study as it will not affect your medical care in any way.

What will happen to the data collected?

All material with personal information will be kept only by researchers if in use or in a locked cabinet in UCL that can only be accessed by research staff. Transcripts of interviews will be anonymised so you cannot be identified and the information you disclose will not be discussed with anyone outside of the research team.

Transcripts and audio recordings will be kept for a period of 20 years after the study is complete, in accordance with the UCL Records Management Policy.

What if there is a problem?

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff you may have experienced due to your participation in the research, National Health Service or UCL complaints mechanisms are available to you. Please ask your research doctor if you would like more information on this.

In the unlikely event that you are harmed by taking part in this study, compensation may be available.

If you suspect that the harm is the result of the Sponsor's (University College London) or the hospital's negligence then you may be able to claim compensation. After discussing with your research doctor, please make the claim in writing to Professor Gill Livingston who is the Chief Investigator for the research and is based at The Mental Health Sciences Unit, Charles Bell House, 67-73 Riding House Street, London W1P 7NN. The Chief Investigator will then pass

the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

What will happen to the results of the research study?

We intend to publish results in relevant conference proceedings and publications and as leaflets and internet resources to help future carers. Please tell the researchers if you would like a copy of any publications and we would be happy to send this to you when it is published. You will not be identified in any report/publication.

Who is organising and funding the research?

The study is being organised by UCL and local PCTs. The study is funded by the National Institute of Health Research.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given a favourable opinion by the NRES Committee London - Fulham.

If you have any questions please contact Dr Naaheed Mukadam (0207 561 4218 or n.mukadam@ucl.ac.uk) or Professor Gill Livingston (020 7561 4218 or g.livingston@ucl.ac.uk).

Thank you for taking the time to read this information sheet.

Appendix 5: Qualitative study consent form

UCL Division of Psychiatry
6th Floor, Wings A and B, Maple House,
149 Tottenham Court Road,
London W1T 7NF

Telephone: 0207 679 9467

Fax: 0207 288 3411

CONSENT FORM – FOCUS GROUP

Title of Project: Improving access to dementia services for minority ethnic elders

Names of Researchers: Dr. Naaheed Mukadam, Dr. Claudia Cooper, Professor Gill Livingston

Participant reference number for study:

Please initial in the box

1. I confirm that I have read and understood the information sheet dated 05/11/2012 Version 1.3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my legal or medical rights being affected. ☐

3. I understand that the focus group will be audio-taped and transcribed as described in the information sheet and that anonymous quotes from these interviews could be used in publications and reports. ☐

4. I understand that relevant data collected during the study, may be looked at by individuals from UCL, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data. ☐

5. I agree to take part in this study. ☐

Name of participant (Print)	Signature of participant	Date
Name of researcher (Print)	Signature of researcher	Date

Appendix 6: English leaflet

So what should you do if you or someone you know has memory problems?

Doing the best for you and your family means seeing your doctor as soon as possible and they can refer you to a memory service if needed.

More Information can be obtained from the following sources:
Alzheimer's Society website: http://www.alzheimers.org.uk/
Alzheimer's Society helpline: Call 0300 222 11 22

NHS
National Institute for Health Research

UCL

NHS

Getting help for memory problems

Case study:
Mrs Chaudhry forgets things. She never used to be like this but now she forgets names, appointments and where she puts things.

She thinks she is just getting older but this isn't normal behaviour for her.

Her family is worried what others will think if they take her to the doctor and she is embarrassed about her problems.

But her family also worry things will get worse if she doesn't get help.

Memory problems are more common as you get older but they are not a normal part of getting older.

Memory problems can be due to physical health problems, stress or sometimes dementia.

If you or someone you know has memory problems, you should see your GP as soon as possible.

They can do blood tests to rule out some physical illnesses and can send you to a memory specialist for further assessment if needed.

Getting help early means you can be reassured if nothing is wrong, or you can get medication and support earlier if anything is wrong.

Getting a diagnosis early means you are doing your best for the person with memory problems.

Dementia is a brain illness that affects a person's memory or their ability to do things and sometimes even their behaviour or personality. Getting help for it means you can get advice and support early and plan for the future better. Having a diagnosis doesn't mean you will be very unwell or that your family cannot look after you but you can all get more help if you want it.

Dementia is a physical illness just like any other illness and you can get help to make things better. It is nothing to be ashamed of and getting a diagnosis sooner leads to a person staying in good health for as long as possible.

Appendix 7: Bengali leaflet

স্মৃতির সমস্যার জন্যে উপদেশ

মিসেস চৌধুরী কিছু কিছু জিনিস ভুলে যান। তিনি আগে এরকম ছিলেন না কিন্তু এখন নাম, কারো সাথে দেখা করার সময়, বা জিনিসপত্র কোথায় রাখেন সব ভুলে যান।

তাঁর ধারনা তাঁর বয়স বাড়ছে বলে এরকম হচ্ছে কিন্তু এটা তাঁর স্বাভাবিক ব্যবহার নয়।

তাঁর পরিবারে সবাই ভাবে তাঁকে ডাক্তার-দেখানো হলে অন্যরা কি ভাববে, তিনিও তাঁর সমস্যা নিয়ে বিব্রতবোধ করেন।

পরিবারের সবাই আবার এটাও ভাবেন যে সাহায্য না পেলে তাঁর অবস্থা আরও খারাপ হবে।

অতএব আপনার বা পরিবারের বা পরিচিত কারও স্মৃতিশক্তির সমস্যা হলে আপনার কি করা উচিত?

আপনার এবং আপনার পরিবারের পক্ষে সবচেয়ে ভালো হয় যদি তাড়াতাড়ি আপনার ডাক্তারের সঙ্গে দেখা করেন এবং দরকার হলে তিনি স্মৃতিরোগ বিশেষজ্ঞের কাছে সাহায্য চাইতে পারেন।

আরো তথ্য এখান থেকে পাওয়া যাবে :
Alzheimer's Society website: http://www.alzheimers.org.uk/
Alzheimer's Society helpline: Call 0300 222 11 22

National Institute for Health Research

স্মৃতির সমস্যা বয়স বাড়লে অনেক লোকের হয়, কিন্তু এটা বয়সের স্বাভাবিক সমস্যা নয়।

স্মৃতির সমস্যা বিভিন্ন কারণে হতে পারে - শারিরীক অসুস্থতা, মানসিক চাপ বা স্মৃতিভ্রংশ অসুখের জন্যও হতে পারে। স্মৃতিভ্রংশকে ইংরেজিতে ডিমেনসা বলে।

যদি আপনার বা আপনার পরিবারের কারও স্মৃতির সমস্যা হয় তবে আপনার ডাক্তারের সঙ্গে যত তাড়াতাড়ি সম্ভব দেখা করুন। কারণ তাহলে তিনি রক্তপরিক্ষা করে কিছু অসুখ বাদ দিতে পারেন এবং দরকার হলে স্মৃতিরোগ বিশেষজ্ঞের কাছে পাঠাতে পারেন।

তাড়াতাড়ি সাহায্য চাইলে যদি কোনো অসুখ না থাকে তাহলে নিশ্চিন্ত হওয়া বা যদি অসুখ হয় তাহলে তাড়াতাড়ি চিকিত্সা ও সাহায্য পাওয়া যায়।

আপনি রোগীর সাহায্য করতে চাইলে সব থেকে উপকারী কাজ তাড়াতাড়ি ডাক্তার দেখিয়ে সময়মতো স্মৃতি সমস্যা রোগের কারণ নির্ণয় করা।

স্মৃতিভ্রংশ একটা মস্তিষ্কের অসুখ এবং এটা কখনো রোগীর স্মৃতিকে, কোনো কিছুর করার ক্ষমতা, ব্যবহার এবং ব্যক্তিত্বকে পরিবর্তন করে।

এই সমস্যার জন্য তাড়াতাড়ি সাহায্য চাইলে সময়মতো উপদেশ এবং সাহায্য পাওয়া যায় যার ফলে
ভবিষ্যতের জন্য ভালো ব্যবস্থা করা যায়।

সঠিক রোগ নির্ণয় করার মানে এই নয় যে আপনি আরও বেশী অসুস্থ হবেন বা আপনার পরিবারের আর দেখাশোনা করতে পারবেন না বরং আপনি চাইলে আরও বেশী সাহায্য পাবেন।

স্মৃতিভ্রংশ অন্য অসুখের মতো একটা শারিরীক অসুখ এবং আপনি এর জন্য সাহায্য পাবেন যাতে আপনার সুবিধে হয়। এতে লজ্জার কিছু নেই এবং তাড়াতাড়ি অসুখ ধরা পড়লে অসুস্থ ব্যক্তি বেশী দিন সুস্থ থাকবেন।

Appendix 8: video script

(Bengali female narrating problems her mother is having with her memory)

Female: My mother has been getting more forgetful for years. We used to laugh it off or ignore it, I don't think anyone in the family was worried.

But then last summer we went to Bangladesh to see family and when we got back she seemed much more confused than usual.

She forgot her granddaughter's birthday party, something she would normally always remember. She started forgetting names and where she has put things.

I needed to help her with cooking, even recipes she knew well as she mixed up spices, and forgot where things were in the kitchen.

I think my mother is embarrassed to see someone about these problems but I am worried she will come to harm – what if she forgets her medication or takes too much? What if she gets worse and gets lost or something?

I think it's better to see a doctor early so we know what is going on.

My friend's aunt didn't get help and she ended up having to go to hospital when she got really bad and that was very stressful.

I think I should make an appointment with the GP for her to make sure she is looked after. What do you think?

Fade to different scene…

Female: I went to see the doctor. She was very helpful. She said I did the right thing to bring my mother and my mother was happy I was looking out for her.

The doctor said that memory problems can be caused by lots of different things, like low vitamin levels. So she took some blood tests to make sure my mother is healthy. She also asked about her mood because sometimes people who have depression can also forget things.

We are waiting for the results now. I hope everything is ok but at least if there is a problem we have hopefully caught it early and can give her treatment.

Next scene…

Female: We got the results of the blood tests. The blood tests were all normal so the doctor said we could see a memory specialist who can do a more detailed assessment to try and find out if she has a memory problem.

The memory clinic doctors saw my mother, they requested a brain scan and saw us with the results. They said my mother has early dementia.

We didn't know what that means – we thought it was something very serious and scary like my grandmother who didn't recognise anyone and couldn't do anything for herself.

But the doctors said that dementia means you have memory problems that are affecting the way you normally do things.

They said it was good we brought her early because she can have medication to slow the illness down.

They also gave us very helpful advice about benefits we can claim and activities that could help my mother stay mentally and physically active.

My uncle was worried that getting help would mean we weren't looking after my mother or that others would interfere too much but that hasn't happened.

We are getting support but still looking after her the way she would like. After all, if she had high blood pressure or diabetes we would make sure she saw a doctor straight away and dementia is also a physical problem that needs help.

Fade into next scene…

Female: My mother is happy. She still does the things she loves and we have become closer because I try and see her more since I know she struggles with some things. I am happy I got help for her as early as possible.

Mother: I was worried when I started having memory problems and I didn't want to see the doctor about it. When I saw the doctor, they made sure my physical health problems like my diabetes were treated and that improved my memory a lot. Now I feel better knowing the cause for my memory problems and I am well supported by my family. I am so glad I got help early for my memory problems.

End message – voiceover: Dementia is a physical illness just like any other physical illness. Doing the best for you and your family means seeing your doctor as soon as possible if you have memory problems and they can refer

you to a memory service if needed. Getting a diagnosis sooner leads to a person staying in good health for as long as possible

If you see your doctor straight away, you can be reassured if there is nothing wrong or get help early if there is a problem – why worry needlessly?

Appendix 9: Letter from GP with intervention

GP LETTERHEAD

Date:

Dear

Our GP practice is committed to improving quality of care and raising awareness about important health conditions. As part of this commitment, we are working with UCL to raise awareness about dementia, particularly in the South Asian community. We have enclosed some information about dementia with this letter and hope you will look at it and find it of interest. This is to raise awareness of this condition and the importance of seeking help early. We are not sending you this information because we suspect memory problems or dementia to be a concern for you or your family. However, if you have significant concerns about your memory, please make an appointment to see your doctor.

Yours sincerely,

NAME OF GP

Appendix 10: Service Support cost award letter

NHS
National Institute for Health Research

Clinical Research Network
North Thames

noclor NHS
Research Support Services

1st Floor, Bloomsbury Building,
St. Pancras Hospital, 4 St Pancras Way,
London NW1 0PE
Tel: 020 3317 3038
Fax: 020 7685 5830

Dr Naaheed Mukadam
Division of Psychiatry
6th Floor, Maple House
149 Tottenham court road
London
W1T 7NF

Ref: Noclor 15/16-0019

10th September 2015

Dear Dr Mukadam,

RE: EAST – DEM Study

On behalf of the **NIHR Clinical Research Network: North Thames** we have considered your application and I am pleased to inform you that we will provide a total of **£5,231.00** from April 2015 to March 2016 to cover eligible service support cost for your study. Please note that the total spending must not exceed the award mentioned in **Appendix 1** unless agreed with us in advance.

Also enclosed with this form is a service support claim form which has to be completed by the study coordinator or a member of the research team and handed to practices each time they are due payment and an invoice is to be raised. All invoices must have a completed service support claim form attached otherwise payment will be delayed. These should be sent by post to the address indicated on the form.

It is the responsibility of the study team to keep records of all GP practices involved in the study and also making sure that these practices are invoicing promptly and for the correct amounts. You are required to provide a progress report on expenditure every quarter since further funding will not be confirmed until a satisfactory report has been received.

We hope this funding will be helpful to your research however if you have any questions or need any further support please feel free to contact us at finance.noclor@nhs.net.

Kind regards

[redacted]

Lynis Lewis/ **Divisional Lead**
R&D Finance CNWL | Camden Provider Services
t: 020 3317 3037 | f: 020 7685 5799

Providing Research Management and Governance Support

Appendix 11: Ethical approval and amendments

NHS
Health Research Authority

National Research Ethics Service

NRES Committee London - Fulham
HRA NRES Centre Manchester
Barlow House
3rd Floor, 4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7821
Facsimile: 0161 625 7299

08 October 2012

Professor Gill Livingston
Professor of Psychiatry of Older People
University College London
Mental Health Sciences Unit
Charles Bell House
67-73 Riding House Street, London
W1P 7NN

Dear Professor Livingston

Study title:	**Improving access to UK dementia services for the South Asian minority ethnic population: development and pilot of an intervention.**
IRAS Project Number:	**73559**
REC reference:	**12/LO/1584**
Protocol number:	**12/0337**

Thank you for your email of 01 October 2012, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

NHS
Health Research Authority

National Research Ethics Service

NRES Committee London - Fulham
HRA NRES Centre Manchester
Barlow House
3rd Floor, 4 Minshull Street
Manchester
M1 3DZ

Tel: 0161 625 7821
Fax: 0161 625 7299

22 January 2013

Professor Gill Livingston
Professor of Psychiatry of Older People
University College London
Mental Health Sciences Unit
Charles Bell House
67-73 Riding House Street, London
W1P 7NN

Dear Professor Livingston

Study title:	**Improving access to UK dementia services for the South Asian minority ethnic population: development and pilot of an intervention.**
REC reference:	**12/LO/1584**
Protocol number:	**12/0337**
Amendment number:	**Amendment 1.0**
Amendment date:	**24 December 2012**
IRAS project ID:	**73559**

- The amendment proposes to include an incentive for focus group participants of the study

The above amendment was reviewed on 21 January 2013 by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Participant Information Sheet: Participant information sheet	1.4	19 December 2012
Notice of Substantial Amendment (non-CTIMPs)	Amendment 1.0	24 December 2012

NHS
Health Research Authority

National Research Ethics Service

NRES Committee London - Fulham
HRA NRES Centre Manchester
Barlow House
3rd Floor, 4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7821
Facsimile: 0161 625 7299

05 June 2013

Professor Gill Livingston
Professor of Psychiatry of Older People
University College London
Mental Health Sciences Unit
Charles Bell House
67-73 Riding House Street, London
W1P 7NN

Dear Professor Livingston

Study title:	**Improving access to UK dementia services for the South Asian minority ethnic population: development and pilot of an intervention.**
REC reference:	**12/LO/1584**
Protocol number:	**12/0337**
Amendment number:	**1.1**
Amendment date:	**19 April 2013**
IRAS project ID:	**73559**

- Amendment to provide a new participant information sheet and consent form for participants who only complete the questionnaire and do not take part in the focus group

The above amendment was reviewed on 04 June 2013 by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Participant Consent Form	1.0	18 April 2013
Participant Information Sheet	1.0	18 April 2013
Notice of Substantial Amendment (non-CTIMPs)	1.1	19 April 2013

Appendix 12: Information sheet for GPs

6th Floor, Maple House
University College London
149 Tottenham Court Road
London
W1T 7NF

Telephone: 0207 679 9467
Fax: 0207 288 3411

GP information sheet: Encouraging Access for South Asians to Timely Dementia Diagnosis (EAST-Dem)

Thank you for your interest in the EAST-Dem study.

What is the purpose of the study?
We aim to recruit six GP surgeries to provide a total of 80 to 100 participants for this pilot study. The aim of this study is to pilot an intervention to encourage earlier help-seeking for dementia in South Asian communities through an evidence-based intervention leaflet and DVD and a personalised GP letter specifically designed for this group. Timely diagnosis of dementia will enable access to treatment, advice and support for individuals at risk and their family and carers. This intervention was developed through discussions with various groups of South Asian community members, memory service professionals, patient and carer representatives and graphic designers. We intend to send the leaflet with the personalised GP letter to South Asian adults without dementia over the age of 50 in the practice.

What will GP practices have to do if they take part?
GP practices will search their databases to identify potential participants (South Asian adults without known dementia aged > 50) and send them a letter asking them to opt into the study by either contacting the researchers or returning a reply slip to the researchers and providing their contact details.

Costs
We have secured service support costs from NHS North Thames Clinical Research Network (CRN) to reimburse GP practices for the time staff spend on activities associated with the study.

How will the intervention be delivered?
GP practices will be allocated either to the intervention group or the control group. Patients who consent to the study will be sent a personalised GP letter and the leaflet and DVD of evidence-based information in the intervention group or no additional information in the control group. Patients will then be asked to consent to a face to face interview with the research team at 2 weeks and after 3 months to fill in a questionnaire about attitudes towards seeking help for dementia.

All information collected during the study will be kept strictly confidential. The study is being funded by the National Institute of Health Research. It has ethics approval from the NRES Committee – Fulham.

For further information or discussion please contact: Naaheed Mukadam (07960 589367 or n.mukadam@ucl.ac.uk)

Best wishes
Gill Livingston (lead)

Appendix 13: Letter about study from GP

GP LETTERHEAD

Date: <<date4>>

Dear <<title>> <<fullname>>,
Our GP practice has been selected to take part in a research study being carried out by University College London. I am writing to you to ask if you would be interested in taking part in this research. The study would involve being sent some information in the post and then being interviewed by a researcher twice for around 20-30 minutes each time.

If you would like to take part, a researcher from UCL will contact you in about two weeks time and ask to see you at home if that suits you or otherwise you can go to them. They will also give you a £20 voucher for meeting them as you are giving up your time to help.

If you are happy to take part, you can contact Dr Naaheed Mukadam (email: n.mukadam@ucl.ac.uk or Telephone: 0207 6799251, Mobile: 07960 589367) or you can write your name and contact details on the slip at the bottom of this letter and return it to the researchers in the enclosed envelope.

Yours sincerely,

<<gp name>>

PLEASE COMPLETE YOUR DETAILS BELOW THEN TEAR OFF THIS SLIP AND RETURN IT IN THE ENVELOPE PROVIDED

I would like to take part in this study and am happy for the researchers to contact me

Name:

Address:

Telephone number:

Appendix 14: Participant information sheet for RCT

6th Floor, Maple House,
149 Tottenham Court Road,
London W1T 7NF

Telephone: 0207 679 9467

Fax: 0207 288 3411

Participant information sheet: Improving access to dementia services for minority ethnic elders – questionnaire study

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

We are interested in the general public's perception of certain illnesses. Understanding how people view certain illnesses can help us to encourage people to seek help earlier for medical problems and improve public health.

Why have I been invited?

Our previous research has shown that South Asian people sometimes have a different way of thinking about certain illnesses compared to the majority ethnic population in the UK and this sometimes means they seek help later for some illnesses which may make their health outcomes less good. We wish to gain a better understanding of health beliefs in order to improve health for people from all ethnic groups. You are not being approached for this research because your GP believes you are suffering from any specific illness.

Do I have to take part?

It is up to you to decide. Please read this information sheet carefully and think about any concerns you may have. If you agree to see us or want to talk on the phone, we can discuss the study in more detail with you and answer any questions or concerns you may have. We will then ask you to sign a consent form to show you have agreed to take part and you will be given a signed copy to keep.

You are free to withdraw from the study at any time, without giving a reason. If you withdraw from the study, you can also request that we not use any of the information you may have already given us. Any stored data that can still be identified as yours will be destroyed if you wish.

What will happen to me / what will I have to do if I take part?

One of the researchers, Dr. Naaheed Mukadam, will contact you in the next two weeks or so to ask if you would like to participate. If you do agree to participate, she will arrange to meet you at a time and place that is convenient for you. She can visit you at home, or arrange for this to be at one of our premises in central London. She will meet you on your own or with a friend or relative of yours if you wish. We can also arrange for an interpreter to be present if you would like this.

The interview will last about 20 minutes and we will ask you personal details (e.g. age, occupation) as they may be relevant. We will then go through a questionnaire exploring your ideas about a particular health topic.

Your name will not be recorded on the questionnaire and all information will be confidential outside the study.

We will contact you again about three months after the initial interview and ask to meet again to go through the same questionnaire to see if anything has changed in that time period.

Expenses and payments

Dr. Mukadam is able to interview you in your own home. If you prefer to be interviewed at one of our research sites then we can reimburse your travel costs. In addition, as a small token of our appreciation for your time and your input, we are able to offer you £20 in high street vouchers.

What are the possible disadvantages of taking part?

We do not foresee there being risks associated with the study. We do however appreciate that completing the two interviews will take up your time.

The interview will be arranged at a time and place of your choosing, so that it causes the least disruption and inconvenience to you.

There are no right or wrong answers to the questions as we are just interested in your own view on these health topics. It is possible that some topics discussed may be upsetting, for example if you or someone you know has experienced these illnesses. We will of course bear this in mind and will not require you to discuss anything that you find uncomfortable or sensitive. If at anytime during the interview you find a topic sensitive or upsetting you can ask the interviewer to move on to another subject or terminate the session altogether. If you

feel upset by the interview you can speak to the researcher who can give you the contact details for the relevant support service.

What are the possible benefits of taking part?

We cannot promise the study will help you but your participation may help to improve the health services we provide.

Will my taking part in the study be kept confidential?

Yes. All interviews are confidential and anonymous so your name will not be disclosed to anyone else and neither will you be identified in any report/publication. If any person in the study tells us that they or someone else is being harmed we will ask their permission to disclose the information to their GP or Consultant Psychiatrist. We respect confidentiality but cannot keep it a secret if anyone is being seriously harmed.

Professional standards of confidentiality will be adhered to and the handling, processing, storage and destruction of data will be conducted in accordance with the Data Protection Act (1998).

Some study documents may also be looked at by authorised representatives from University College London (UCL) Research & Development Unit to check that the study is being carried out correctly. Professional standards of confidentiality will be followed by the authorised representatives.

The information you provide will only be used for the purposes for this research study and not for any other purpose.

Involvement of the General Practitioner/Family doctor (GP)

Your GP practice has agreed to take part in this study which is how we came to contact you. GP practices that are taking part in the study will be randomly allocated to either do nothing or to send their eligible South Asian patients some information on a health topic. We will not be altering your medical treatment in any way. Your medical care will not be affected regardless of whether you decide to take part in this study or not.

What will happen to the data collected?

All material with personal information will be kept only by researchers if in use or in a locked cabinet in UCL that can only be accessed by research staff. Paper records will be kept for a period of 20 years in accordance with the UCL Records Management Policy.

What if there is a problem?

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff you may have experienced due to your participation in the research, National Health Service or UCL complaints mechanisms are available to you. Please ask your research doctor if you would like more information on this.

In the unlikely event that you are harmed by taking part in this study, compensation may be available.

If you suspect that the harm is the result of the Sponsor's (University College London) or the hospital's negligence then you may be able to claim compensation. After discussing with your research doctor, please make the claim in writing to Professor Gill Livingston who is the Chief Investigator for the research and is based at UCL Division of Psychiatry, 6th Floor, Wings A and B, Maple House,149 Tottenham Court Road, London W1T 7NF. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

What will happen to the results of the research study?

We intend to publish results in relevant conference proceedings and publications and as leaflets and internet resources to help future carers. Please tell the researchers if you would like a copy of any publications and we would be happy to send this to you when it is published. You will not be identified in any report/publication.

Who is organising and funding the research?

The study is being organised by UCL. The study is being funded by The National Institute for Health Research

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given a favourable opinion by the NRES Committee London - Fulham.

If you have any questions please contact Dr Naaheed Mukadam (020 7679 9251 or n.mukadam@ucl.ac.uk) or Professor Gill Livingston (020 7561 4218 or g.livingston@ucl.ac.uk).

Thank you for taking the time to read this information sheet.

Appendix 15: Consent form for RCT

6th Floor, Maple House,
149 Tottenham Court Road,
London W1T 7NF

Telephone: 0207 679 9251

Fax: 0207 288 3411

CONSENT FORM – QUESTIONNAIRE STUDY

Title of Project: Improving access to dementia services for minority ethnic elders

Name of Researcher(s): Dr. Naaheed Mukadam, Dr. Claudia Cooper, Professor Gill Livingston

Participant reference number for study:

Please initial in the box

1. I confirm that I have read and understood the information sheet dated 21/10/2015 Version 1.4) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my legal or medical rights being affected. ☐

3. I understand that relevant data collected during the study, may be looked at by individuals from UCL, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data. ☐

4. I agree to take part in the above study ☐

Name of participant (Print)	Signature of participant	Date
Name of researcher (Print)	Signature of researcher	Date

Appendix 16: Baseline questionnaire

Thank you for agreeing to participate. Please ask us for help if anything is not clear.

Please read the story below and then answer the questions that follow.

Imagine that Mrs Chaudry is a 70 year old close relative of yours. Family members have noted that she is more forgetful lately. She cannot remember conversations with people and forgets appointments with her doctor. She often misplaces important things like her keys and glasses. She is physically healthy but is concerned about her memory.

In order to answer the following questions please imagine that you are experiencing memory problems like Mrs Chaudry. Please respond to each question by circling a number between 1 and 7. Unless otherwise indicated use the scale below:

Strongly Disagree	Disagree	Disagree Somewhat	Neutral	Agree Somewhat	Agree	Strongly Agree
1	2	3	4	5	6	7

1. If I had memory problems like Mrs Chaudry, I would seek help from my doctor: Strongly Strongly disagree 1 2 3 4 5 6 7 agree	6. I am confident that I would be able to see my doctor for memory problems if I wanted to: Strongly Strongly disagree 1 2 3 4 5 6 7 agree
2. I would expect to go to see my doctor for help, if I had memory problems: Strongly Strongly disagree 1 2 3 4 5 6 7 agree	7. Most people who are important to me would approve of seeking help from my doctor for memory problems: Strongly Strongly disagree 1 2 3 4 5 6 7 agree

3. I would want to go to see my doctor if I had memory problems: Strongly Strongly disagree 1 2 3 4 5 6 7 agree	8. It would be expected of me that I would see my doctor for memory problems: Strongly Strongly disagree 1 2 3 4 5 6 7 agree
4. It would be easy to seek help from my doctor for memory problems: Strongly Strongly disagree 1 2 3 4 5 6 7 agree	9. Overall, I think seeking help from my doctor for memory problems would be: Useless 1 2 3 4 5 6 7 Valuable
5. It would be my decision whether or not to see my doctor for memory problems: Strongly Strongly disagree 1 2 3 4 5 6 7 agree	10. Overall, I think seeking help from my doctor for memory problems would be: Bad 1 2 3 4 5 6 7 Good
11. My doctor would be able to provide treatments to help with memory problems: Strongly Strongly disagree 1 2 3 4 5 6 7 agree	16. For memory problems, finding out about what services are available to help would be desirable: Strongly Strongly disagree 1 2 3 4 5 6 7 agree
12. My doctor would be able to tell me what the cause of memory problems is: Strongly Strongly disagree 1 2 3 4 5 6 7 agree	17. Getting help from my doctor for memory problems would be embarrassing: Strongly Strongly disagree 1 2 3 4 5 6 7 agree
13. My doctor would be able to tell me what services are available to help with memory problems: Strongly Strongly disagree 1 2 3 4 5 6 7 agree	18. My family would think that I should seek help from my doctor for memory problems: Strongly Strongly disagree 1 2 3 4 5 6 7 agree
14. For memory problems, a treatment to help would be desirable:	19. What my family thinks I should do is important to me:

Strongly Strongly disagree 1 2 3 4 5 6 7 agree	Strongly Strongly disagree 1 2 3 4 5 6 7 agree
15. For memory problems, finding out about the cause would be desirable: Strongly Strongly disagree 1 2 3 4 5 6 7 agree	**Thank you for completing this questionnaire**

For researchers use:

Theory of Planned Behaviour	Items			Analysis
Intention to seek help	1= ☐	2= ☐	3= ☐	Sum (1, 2, 3) =____
Behavioural attitudes	9= ☐	10=☐		Sum (9, 10) = ____
Subjective norms	7= ☐	8= ☐		Sum (7, 8) = ____
Perceived behavioural control	4= ☐	5= ☐	6= ☐	Sum (4, 5, 6) = ____
Behavioural beliefs	11=☐	12=☐	13=☐	
Outcome evaluations	14=☐	15=☐	16=☐	
Expectancy value calculation	11*14	12*15	13*16	Sum =_____
Normative beliefs	17=☐	18=☐		
Motivation to comply	19=☐			
Expectancy value calculation	17*(-1)	18*19		Sum =_____

The questions below are about dementia. Please tick the boxes to answer the questions. If you are not sure of the answer, please make your best guess.

1. Which part of the body is affected in dementia? (Please tick one of the following) Lungs ☐ Brain ☐ Heart ☐ Don't know ☐

2. Dementia mostly affects people aged: (Please tick one box below)
30–40 years ☐ 40–60 years ☐ Over 60 years ☐ Don't know ☐

3. Is there a cure for dementia? (Please tick one box below)
Yes ☐ No ☐ Don't know ☐

4. How many types of dementia are there? (Please tick one box below)
One ☐ Two ☐ Three or more ☐ Don't know ☐

5. What percentage of people over 65 years of age have dementia? (Please tick one box)
Less than 5% ☐ 5–20% ☐ 20–50% ☐ 50–70% ☐ 70–100% ☐
Don't know ☐

6. Which factors can cause dementia? (Please tick all of the following that apply)
Diet ☐ Infection ☐ Hereditary factors ☐ Stroke ☐ Alcohol ☐ Old age ☐

7. Dementia can affect the following: (Please tick all of the following that apply)
Vision ☐ Personality ☐ Reasoning ☐ Memory ☐ Mobility ☐ Speech ☐
Incontinence ☐ Life expectancy ☐

Please answer the questions below, which ask you to provide information about yourself.

1. What is your gender?
   Male☐ Female☐

2. How old are you?
   Age in years _____ **Or** Date of birth _____

3. What is your marital status:
   Single☐ Married or ☐ Divorced☐ Separated☐ Other (Please specify):
   living with partner

4. How would you describe your ethnicity:
Indian☐ Pakistani☐ Bangladeshi☐ Sri Lankan☐ Mixed☐ Other (specify): _____

5. What is your religion? (Please state below)
   _____

6. What is your country of birth? (Please state below)
   _____

7. If you were not born in the UK, in what year did you come to UK? (Please state below)
   _____

8. What is your first language? (Please state below)
   _____ Interpreter needed? Yes/No

9. What age did you leave full-time education? (Please state below)
   _____

10. What is your current employment status:
    Employed ☐Retired ☐ Unemployed☐ Other (please specify)_____

11. What is your current or previous occupation (if not working)? (Please state below)

12. Has anyone you have known well had dementia or Alzheimer's disease?
    Yes☐ No☐

13. Have you ever cared for a family member or friend with dementia or Alzheimer's
    disease?
    Yes ☐ No ☐

14. Has your job ever involved working with people who have dementia?
Yes ☐ No ☐

15. Have you ever seen your doctor for memory problems?
Yes ☐ No ☐ If yes, when and what was outcome?

16. Did you get a leaflet and DVD about memory problems from your GP in the post recently?
Yes ☐ No ☐ If yes, please answer the following questions.

17. Did you find it acceptable to receive these items in the post? (please circle one response)

1	2	3	4	5
Completely unacceptable	Somewhat unacceptable	Neither acceptable nor unacceptable	Somewhat acceptable	Completely acceptable

18. Did you look at the materials?
Yes, both leaflet and DVD ☐ Leaflet only ☐ DVD only ☐ Neither ☐

19. What did you think about the materials you saw?

20. What did you think the key messages were?

21. Do you think we should make any changes to the leaflet or DVD?

22. Any other comments or thoughts?

Appendix 17: Follow-up questionnaire

Thank you for agreeing to participate. Please ask us for help if anything is not clear.

Please read the story below and then answer the questions that follow.

Imagine that Mrs Chaudry is a 70 year old close relative of yours. Family members have noted that she is more forgetful lately. She cannot remember conversations with people and forgets appointments with her doctor. She often misplaces important things like her keys and glasses. She is physically healthy but is concerned about her memory.

In order to answer the following questions please imagine that you are experiencing memory problems like Mrs Chaudry. Please respond to each question by circling a number between 1 and 7. Unless otherwise indicated use the scale below:

Strongly Disagree	Disagree	Disagree Somewhat	Neutral	Agree Somewhat	Agree	Strongly Agree
1	2	3	4	5	6	7

1. If I had memory problems like Mrs Chaudry, I would seek help from my doctor: Strongly Strongly disagree 1 2 3 4 5 6 7 agree	6. I am confident that I would be able to see my doctor for memory problems if I wanted to: Strongly Strongly disagree 1 2 3 4 5 6 7 agree
2. I would expect to go to see my doctor for help, if I had memory problems: Strongly Strongly disagree 1 2 3 4 5 6 7 agree	7. Most people who are important to me would approve of seeking help from my doctor for memory problems: Strongly Strongly disagree 1 2 3 4 5 6 7 agree

3. I would want to go to see my doctor if I had memory problems: Strongly Strongly disagree 1 2 3 4 5 6 7 agree	8. It would be expected of me that I would see my doctor for memory problems: Strongly Strongly disagree 1 2 3 4 5 6 7 agree
4. It would be easy to seek help from my doctor for memory problems: Strongly Strongly disagree 1 2 3 4 5 6 7 agree	9. Overall, I think seeking help from my doctor for memory problems would be: Useless 1 2 3 4 5 6 7 Valuable
5. It would be my decision whether or not to see my doctor for memory problems: Strongly Strongly disagree 1 2 3 4 5 6 7 agree	10. Overall, I think seeking help from my doctor for memory problems would be: Bad 1 2 3 4 5 6 7 Good
11. My doctor would be able to provide treatments to help with memory problems: Strongly Strongly disagree 1 2 3 4 5 6 7 agree	16. For memory problems, finding out about what services are available to help would be desirable: Strongly Strongly disagree 1 2 3 4 5 6 7 agree
12. My doctor would be able to tell me what the cause of memory problems is: Strongly Strongly disagree 1 2 3 4 5 6 7 agree	17. Getting help from my doctor for memory problems would be embarrassing: Strongly Strongly disagree 1 2 3 4 5 6 7 agree
13. My doctor would be able to tell me what services are available to help with memory problems: Strongly Strongly disagree 1 2 3 4 5 6 7 agree	18. My family would think that I should seek help from my doctor for memory problems: Strongly Strongly disagree 1 2 3 4 5 6 7 agree
14. For memory problems, a treatment to help would be desirable:	19. What my family thinks I should do is important to me:

Strongly Strongly disagree 1 2 3 4 5 6 7 agree	Strongly Strongly disagree 1 2 3 4 5 6 7 agree
15. For memory problems, finding out about the cause would be desirable: Strongly Strongly disagree 1 2 3 4 5 6 7 agree	**Thank you for completing this questionnaire**

for researchers use:

Theory of Planned Behaviour	Items			Analysis
Intention to seek help	1= ☐	2= ☐	3= ☐	Sum (1, 2, 3) =____
Behavioural attitudes	9= ☐	10=☐		Sum (9, 10) = ____
Subjective norms	7= ☐	8= ☐		Sum (7, 8) = ____
Perceived behavioural control	4= ☐	5= ☐	6= ☐	Sum (4, 5, 6) = ____
Behavioural beliefs	11=☐	12=☐	13=☐	
Outcome evaluations	14=☐	15=☐	16=☐	
Expectancy value calculation	11*14	12*15	13*16	Sum =_____
Normative beliefs	17=☐	18=☐		
Motivation to comply	19=☐			
Expectancy value calculation	17*(-1)	18*19		Sum =_____

The questions below are about dementia. Please tick the boxes to answer the questions. If you are not sure of the answer, please make your best guess.

1. Which part of the body is affected in dementia? (Please tick <u>one</u> of the following) Lungs ☐ Brain ☐ Heart ☐ Don't know ☐

2. Dementia mostly affects people aged: (Please tick one box below)
   30–40 years ☐ 40–60 years ☐ Over 60 years ☐ Don't know ☐

3. Is there a cure for dementia? (Please tick one box below)
   Yes ☐ No ☐ Don't know ☐

4. How many types of dementia are there? (Please tick one box below)
   One ☐ Two ☐ Three or more ☐ Don't know ☐

5. What percentage of people over 65 years of age have dementia? (Please tick one box)
   Less than 5% ☐ 5–20% ☐ 20–50% ☐ 50–70% ☐ 70–100% ☐
   Don't know ☐

7. Which factors can cause dementia? (Please tick <u>all</u> of the following that apply)
   Diet ☐ Infection ☐ Hereditary factors ☐ Stroke ☐ Alcohol ☐ Old age ☐

7. Dementia can affect the following: (Please tick <u>all</u> of the following that apply)

Vision ☐ Personality ☐ Reasoning ☐ Memory ☐ Mobility ☐ Speech ☐

Incontinence ☐ Life expectancy ☐

Please let us know if there has been any change in your personal circumstances since we last met:
